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LITTLE PEOPLE OF AMERICA

NEWS CLIPPINGS

1989 – 2003

For teacher, size not key to stature

TEACHER, from Page 1A

Sometimes ignorance and cruelty reign, such as when people point at him in supermarkets. Depending on who's doing the gawking and his mood, Shepard might explain he is a little person — he shuns "dwarf" as too clinical — or point back. "Or they'll say, 'Look, a midget!' " he said. "And I'll say 'Where?' "

The word midget offends him; he says it was coined by circus folk for little people who were clowns.

Rather than resort to bitterness, Shepard tries to show he is no different from anyone else. He also tries to pass on to his charges the self-esteem that many influential teachers and his parents, a Stanford University psychology professor and a lecturer in children's literature, instilled in him.

"The deal with self-esteem is mainly realizing that it's most important for people to realize that we all are different, but we all have positive things to contribute," Shepard said.

Praises innovation

What he has to offer shines as he helps a new reader sound out a word. Shepard questions students' comprehension as they wend their way through Weekly Reader and praises innovative answers.

> 'It's just the way he is. It doesn't matter if he's small, or big or medium.'
>
> *— Rachael Kleidon, pupil*

To many students, Shepard's gender is more of an issue than his height.

"I had to get used to Mr. Shepard because I hadn't had a boy teacher yet," Beth Aufdemberge said. "And I never had a little person who's been a teacher."

Added her pal Rachael Kleidon: "On the first day of school, it was fun, and it still is and our activities are very fun. I just treat him the same way I would another teacher. It's just the way he is. It doesn't matter if he's small, or big or medium."

Wanting to help others led Shepard into teaching. And by all accounts, teaching has been as rewarding for him as it has been for his students.

"I think it's been a real good year," said Barbara Smith, whose daughter Melinda is in Shepard's class. "No matter what, it's been a great experience for kids."

Shepard is not a pioneer in choosing teaching as his profession, said Harriet Stickney, spokeswoman for Little People of America, a national support group based in San Bruno.

Must establish discipline

As a little person, being a teacher "is a challenge," said Stickney, who taught for 12 years. "You have to establish discipline, because if your class is going to fall apart it might be blamed on the fact that you are a little person."

Discipline and setting the tone in class is especially difficult for first-year teachers, said Ruth Carleton, a first-grade teacher at Palo Verde.

"With many beginning teachers, it's very hard to get a handle on who you are," she said. "And you are the teacher. Getting the children to realize you are the person in charge is always very, very difficult. He has overcome that."

When Shepard started last fall, he "had some trouble with kids listening to him," Smith said. But when he realized the classroom regulations he had posted weren't effective, he had the class help him write new ones.

The revised rules are simple, calling for students to follow directions and not talk when someone else is speaking.

When the class becomes a little noisy, Shepard simply stops. He folds his arms across his chest and waits. It doesn't take long.

During a recent multiplication lesson, he commanded the class from his perch — standing atop a picnic bench. He also uses a bench when he wants to write high on the blackboard.

'Student of the Week' event

Implicit in Shepard's classroom is that each child is important. Each week the spotlight shines on a different "Student of the Week." The chosen student calls the others to recess, leads the line and runs errands to the office. Classmates draw pictures for (often of) the student, which are displayed on a central bulletin board.

Other details of classroom decor also are testament to self-esteem. Shepard had all of his students make posters depicting their good points. Eric Gray's had some dinosaurs and stars and this self-evaluation: "hard-working, neat, dependable."

> 'We all have positive things to contribute.'
>
> *— Todd Shepard*

If Tom Steege, principal of Palo Verde, drew such a poster about Shepard it would be equally flattering. Steege said he hired Shepard because "I consider him an intelligent person, capable of learning."

He should know. He remembers Shepard as a student at the former Stanford Elementary School, where Steege was principal. "He had enough courage within him that he could make his way," Steege said. "He stands up for himself."

Shepard said he was not teased much as he grew up on the Stanford campus. His parents expected him to be treated as everyone else, and Shepard was never segregated in special classes.

"The only way that I felt like it got in my way was I was always picked last for sports," Shepard said, which hurt because he harbored dreams of making varsity teams.

Shepard still enjoys sports — especially basketball. He is a proficient shooter.

After graduating from Gunn High School, Shepard attended the University of California, Davis.

"I knew I wanted to work with kids, or help people in some way," Shepard said.

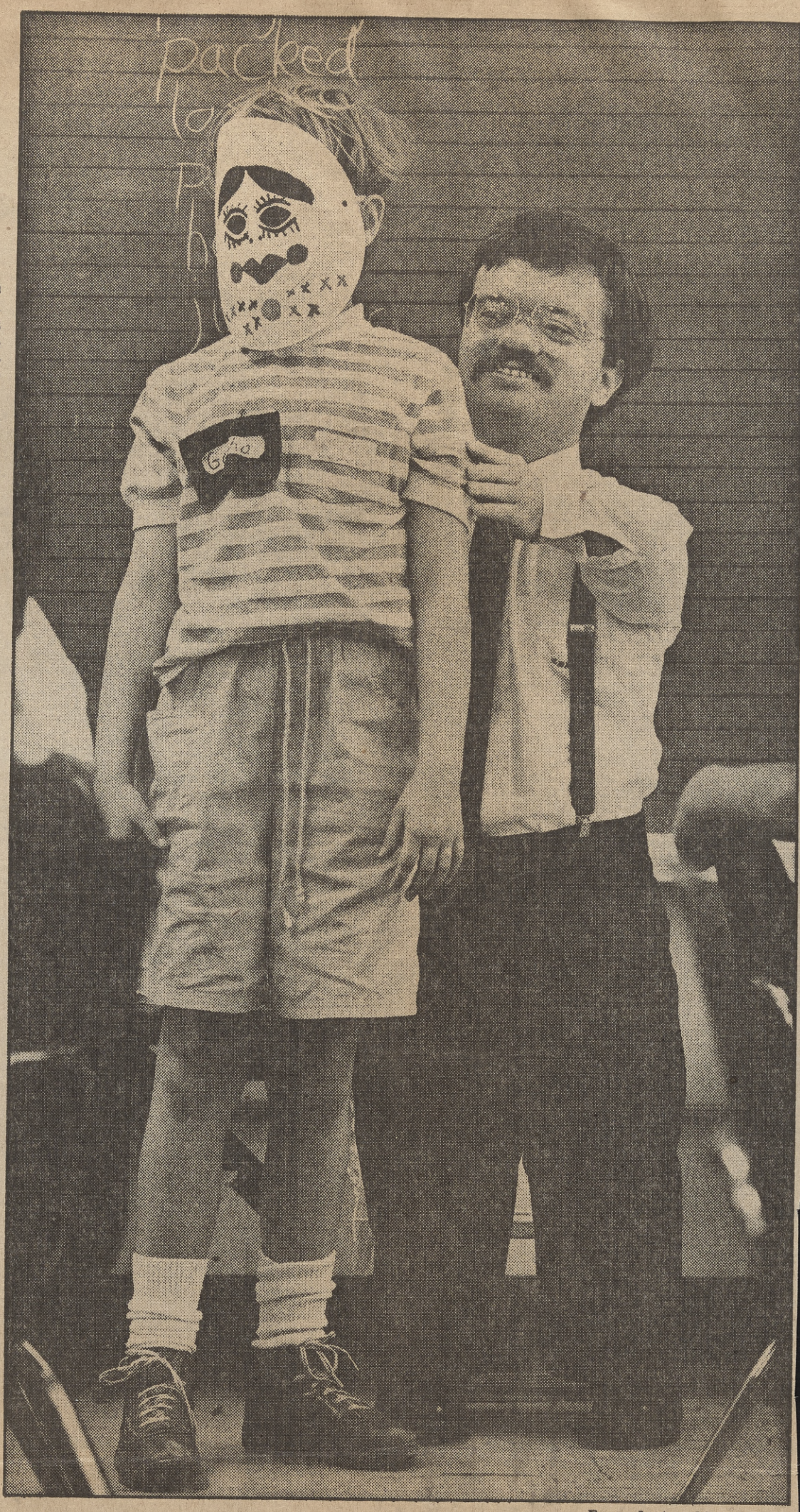
But when he graduated in 1981, there was a glut of teachers. So he became a computer programmer and worked for Lockheed for four years.

"I finally reached a point where enough was enough, and I enrolled in a credential program," he said.

Making that move also impressed Steege: "The change from computers showed that he had a mission and that he held children higher than the almighty dollar.

"I like to see a man on the staff. And it's a society of diversity, and children need to see that at an early age."

Being little, Shepard said, is "considered a handicap. The interesting thing about being a little person is that I don't feel handicapped per se. I feel handicapped to the extent that there's things I can't reach or whatever. But in the end that's not a big deal."



Eugene Louie — Mercury News

SHOW AND TELL — Gosha Samotyj, 8, displays the mask made with the help of teacher Todd Shepard, who helps her as she explains it to the class.

Why 'L.A. Law' Actor Tried to Commit Suicide

"L.A. Law" actor David Rappaport tried to kill himself after TV execs dashed the dwarf performer's desperate hopes for a starring role in his own series — hurling him into a tailspin of despair, say insiders.

It was the third time in four years that he had a shot at series stardom only to see it cruelly yanked away each time. He decided that for him, it was three strikes and out.

On March 4, Rappaport — who played short but shrewd lawyer Hamilton Schuyler on "L.A. Law" — was found inside his car on a remote road in the Hollywood hills. The car's motor was running and a hose led from the exhaust pipe into the backseat.

Near death from carbon monoxide poisoning, the 3-foot-11 actor was rushed to Hollywood's Presbyterian medical center.

"We're treating this as an attempted suicide," said Los Angeles homicide detective Russell Kuster. "Rappaport is lucky to be alive."

The 38-year-old divorced actor was discovered by Rose Berger, manager of Sunset Ranch Hollywood Stables where Rappaport often came to relax on weekends. Rose told The ENQUIRER:

"Right after dark I was driving down the dirt road that leads to the ranch when I saw a VW Rabbit parked on the roadside.

"I knew something was terribly wrong. The engine was running and the lights were out. I went back to the ranch and called police.

"A patrol car arrived within minutes. The patrolman flashed a light on the car and there it was — a hose running from the tail pipe into the backseat.

"The rear window was rolled slightly down to allow the hose inside, and the open space was sealed up with tape.

"The policeman opened the door, and there was poor David lying on the backseat. He wasn't breathing!

"The cop applied mouth-to-mouth resuscitation, and David slowly began coming to."

Rappaport was hospitalized in "serious" condition, but one of his nurses confided: "He's doing fine and I expect him to pull through."

The actor — who starred in the 1981 film "Time Bandits" — had struggled for years to gain respect in Hollywood, a friend said.

Rappaport thought he finally had a chance for stardom when he landed the 1986 TV series "The Wizard." But the show quickly fizzled.

He got a second chance soon afterward when he guested on TV's "Hooperman" and was such a smash that producers planned to star him in a spin-off series. But the show never got off the drawing board, and the actor was devastated.

Then came his meatiest role ever — on "L.A. Law." In a two-part episode that aired in October 1987, he played a cunning lawyer who used his short size to win over juries and confound his opponent Victor Sifuentes, played by Jimmy Smits.

Producers liked him so much they brought him back in the same role in November of last year — and once again he was a hit with viewers.

"After we saw the impact of his character, we started putting together an idea for David to star in a spin-off," confirmed an "L.A. Law" insider.

But months went by and Rappaport heard nothing.

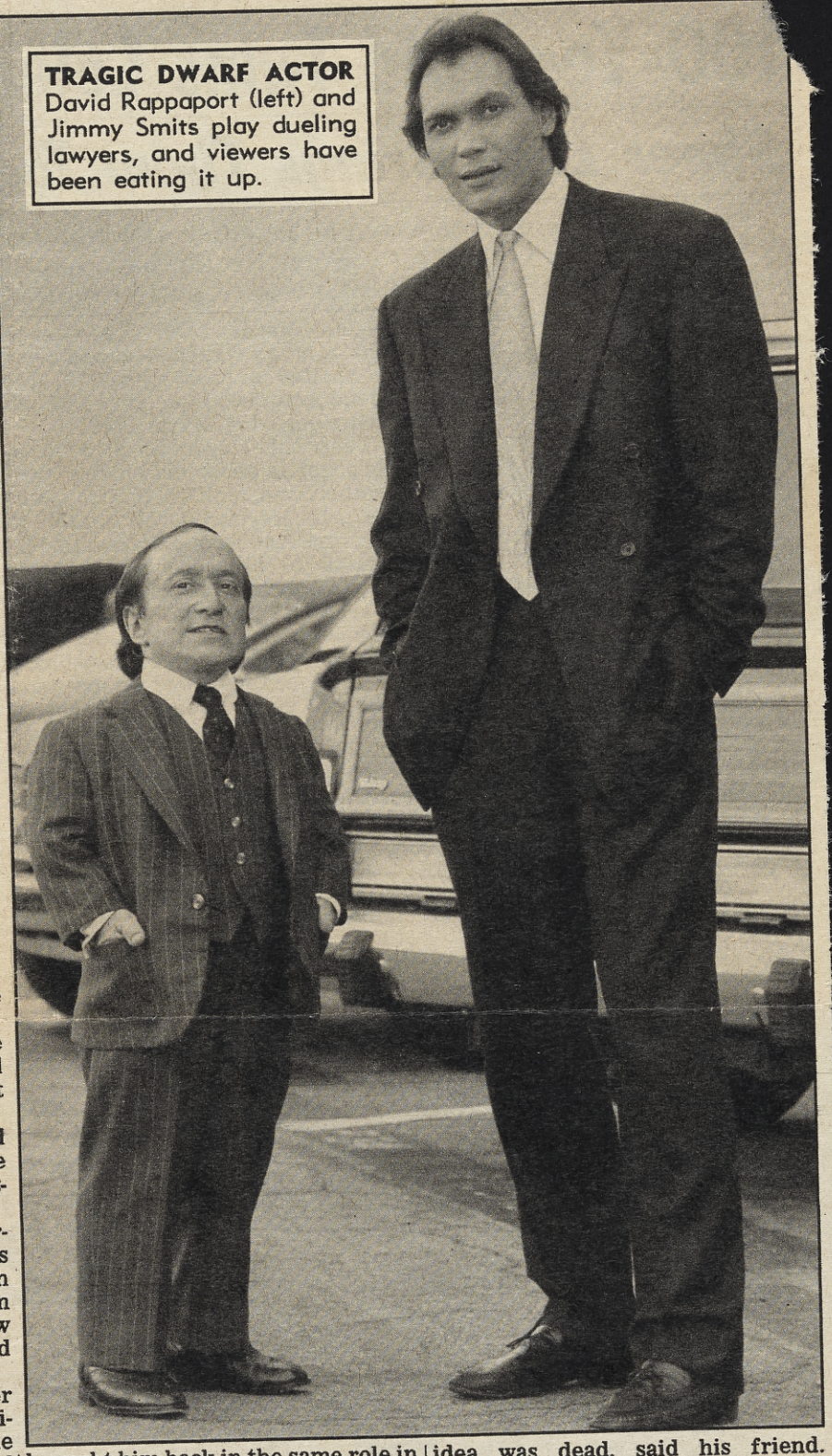
Finally, a few weeks ago, he called producers — and was told the series idea was dead, said his friend.

"That was the final, crushing blow. That's when he tried to do himself in. David was just sick of being dealt bad hands in life."

Said Rose Berger, who found him: "It's so terribly sad. I just pray David works out his problems. He's a wonderful actor."

— JEROME GEORGE, ANGELA AIELLO, ALAN BRAHAM SMITH and MARTIN DRYAN

CANCELED: Rappaport starred in the 1986 TV series "The Wizard" (above), but it went nowhere.



TRAGIC DWARF ACTOR David Rappaport (left) and Jimmy Smits play dueling lawyers, and viewers have been eating it up.

World's Smallest Private Eye Bags the Big Guys

PINT-SIZE detective Lucio Pico takes a call at his office while his secretary checks notes on the case.

4-Ft.-5 Sleuth Even Hid in Luggage to Nab Arms Dealer

Pint-size private eye Lucio Pico is the world's smallest detective — but although he stands only 4-foot-5 he's still the top man on big cases.

"Being a dwarf is the perfect cover," Pico, 26, told The ENQUIRER. "I can work on cases that normal-size guys in my profession would not be able to handle."

Once Pico and another private eye were working together, tracking an arms dealer, and were trying to find out if he had stayed at a certain luxury hotel. But the hotel refused to let them look at the register listing the hotel's guests. The manager kept the register in his office.

"My colleague and I came up with the perfect plan," Pico said. "He bought a huge sports equipment bag and I crawled inside it.

"He carried me down to the hotel's front desk, paid the bill, and said he'd like to leave his bag there until his plane was ready to take off. The manager said, 'Yes, you can lock it in my office.'

"I waited until I heard them lock the door behind me.

"Quickly I climbed out, went straight to the hotel register and took photos of the page with the arms dealer's name. Then I crawled back inside the bag."

Incredibly, Pico's tiny stature also helped him escape injury when two goons jumped him about a year ago.

"I'd been hired to tail a nightclub owner, and I shadowed him all day — but I didn't count on his bodyguards," he recalled. "They spotted me, hid in a dark alley and as I walked past they pounced on me like a couple of gorillas.

"If I were a normal-size guy, the first punch would have knocked me out. But they had to bend their knees to swing down at me. I just ducked and that put me at the level of their knees.

"One of them bent down to grab me, but I dove through the legs of the other one, rolled over three times like a ball, ran as fast as I could and escaped.

"Another time a rich man was worried that his son was going to be kidnapped. I was employed to keep a watch on the youngster at his private school. For weeks I dressed up like a kid in the school's gray uniform and accompanied the boy everywhere.

"Then, sure enough, there was a kidnap attempt. As we got off the school bus, a car stopped and three men began to scramble out toward us. I grabbed the boy and we ran to a busy shopping center, where we lost them.

"What the would-be kidnappers didn't know was that I jotted down their car's license number. I passed it on to police, and they were arrested the following day."

A spokeswoman for the Guinness Book of World Records said they've never heard of a smaller private eye than Pico.

The diminutive detective, who lives in Geneva, Switzerland, says he's proud of his success, adding: "It just goes to show that even dwarfs like me can do well in life."

— *PATRICK WILKINS*

GIANT SUCCESS: Lucio may be small, but on the job he packs a big gun as an equalizer.

PALS: Lucio's dog stands taller than his master.

NATIONAL ENQUIRER (USPS 372-940) Published weekly by National Enquirer, Inc., Lantana, Fla. 33464. Vol. 64, No. 32. MAIL SUBSCRIPTIONS $29.75 a year in U.S., $49.75 a year outside U.S. Second Class postage paid at Lake Worth, Fla., and at additional mailing offices in the U.S.A. Canadian Second Class Postage Permit #9781 paid at Toronto, Ontario, Canada. POSTMASTER: Send address changes to NATIONAL ENQUIRER, P.O. Box 11284, Des Moines, Iowa 50340-1284. For subscription address changes and inquiries write NATIONAL ENQUIRER, P.O. Box 11284, Des Moines, Iowa 50340-1284. Printed in U.S.A.

SLATON SLATONITE, MAY 17, 1990

Lee Kitchens - A Little Person With Big Accomplishments

Lee Kitchens

By Pam Williams
News Editor

Lee Kitchens of Ransom Canyon may be a person of short stature, but his accomplishments tower above his four foot frame. Born with a genetic birth defect that effected his bone growth, Kitchens has traveled around the world through his job and his involvement in "Little People" organizations.

Kitchens has been a technical engineer for Texas Instruments for 38 years. He began as a co-op student his last three years of high school during the infant days of transistors. He spent ten years designing semi-conductors and putting them into production. Because the industry was so new, production equipment didn't exist so he helped design what we would call automation today.

Kitchens spent another ten years–half of them in Lubbock–designing and building calculators and computers.

In the 1970's, TI sent Kitchens to Europe where he spent a year in the Netherlands starting up an operation to build calculators and another ten years in Italy running TI's customer service operation.

In 1983, TI transferred Kitchens to Houston to work on projects related to production in the Far East which he was also able to visit.

Then TI developed a Professor Program in which they loaned senior technicians to universities to teach. The last five years Kitchens has spent teaching industrial engineering at Texas Tech. He doesn't have a doctorate, but he does have an "EXP" degree–experience. He tries to bring "the real world" into the classroom.

Kitchens will retire from TI in August, but already has an appointment to continue his teaching at Tech. His students think he is "tough." He expects of them what he knows will be required on the job. In 1988 Kitchens received the Abell Distinguished Undergraduate Teaching Award from the College of Engineering.

Teaching classes demands only part of Kitchens' time. In 1960 he joined a relatively new organization called the Little People of America (LPA). This group, comprised mostly of people of short stature, was formed as a peer support group to help "little people" deal with issues that anyone different from the "norm" has to deal with...people that stare and make comments, discrimination, employment, education, and transportation.

LPA began in 1957 with 20 members and has grown to over 5000 members today. A West Texas Chapter, formed within the last two years, meets periodically for workshops, entertainment, and recreation. (Kitchens just returned from the annual national conference held in Dallas this year.) From 1964-68, he served as national president of LPA and remained active on the board of directors until 1989.

Kitchens was born in Fort Worth to parents of normal height. His father was a livestock buyer and later a rancher. His sister is of average height and has average height kids. He went through public school in Fort Worth–the only little person in his school and one of two in the Fort Worth schools at the time. The other one could never learn to deal with his short stature and eventually committed suicide.

Kitchens met his wife by accident while attending college. He was engineering manager for a campus radio station at SMU. Word came that a radio station on the TCU campus had gone off the air and needed someone to locate the problem. Kitchens and his roommate went to TCU to repair the technical problem. While there his roommate spotted a young lady walking across campus, found out who she was, and set up a blind date with Kitchens. Mary, the young lady, happened to be from Lubbock and she and Kitchens were married a short time later.

The Kitchens adopted two children. Their son, Alan, lives in Wolfforth and is 5'7". The doctors had said he would be a little person. Alan lived in several foster homes before coming to the Kitchens and was emotionally deprived. After living with the Kitchens a while, he began to thrive and grow although his development always lagged behind the other kids. Their daughter, Sandra, is married and lives in Ransom Canyon. She and her husband have a son of average height and a one-year-old daughter who will be of short stature.

Over 200 types of short stature exist–some genetic, some inherited, and some just mutations or accidental birth defects. Two types are understood and correctable. The most common correctable type is hypo pituitary growth–failure to grow because of the lack of growth hormone. In the 1960's parents desperately sought cures for this type of growth disfunction.

These parents organized to raise money for research into the way growth hormone could be acquired. At the time, the only way was to take it from the pituitary gland of a deceased person. There was never enough to go around. As a result of this effort, the Human Growth Foundation was formed. Kitchens is currently president of this group.

The growth hormone is now synthetically produced but is very expensive. The Foundation tries to locate children who need the hormone through the schools, shopping malls, and screening sessions. A child may be in school before the parent realizes the child will not develop fully. Parents don't alway recognize why the short child is so short until it is too late to correct the hormone imbalance. However, only a small portion of the short stature population can be treated with shots to grow to normal height.

Organizations such as the Little People of America, the Human Growth Foundation, and the International Growth Federation try to educate couples

See KITCHENS, Page FOUR

America's smallest comic gets big, big laughs

Gloria Samuels is a hotshot stand-up comic, but you can barely see her when she stands up!

At just 2 feet 10½ inches tall, she's America's tiniest comedian.

But the pint-size funnylady gets big laughs about her little size.

"I tell audiences that being little is like being on 'Candid Camera' every day," said the 42-year-old mother of two.

"At the store, people want to buy me. When kids come over to the house, they want to play with me instead of my children."

Amazingly, Gloria's 18-year-old son Anthony is a whopping 6-foot-1 — and her daughter Andrea, 14, towers over her at 5-foot-7.

With a body the size of a 3-year-old and the razor-sharp wit of an adult, Gloria says there's no shortage of short jokes for her act.

"I joke about the GTE phone company slogan. They say, 'At GTE, we hear you.' How can they hear me when I can't even reach the phone?" she cracked.

"And the people at Coca-Cola say, 'Have a Coke and a smile.' How can I have a Coke with a smile when I have to wrestle the pop machine to get it out?

"Burger King's slogan is 'Have it your way.' But when I go there, I tell them, 'How can I have it my way when you can't even see me?'

"So I pull into the drive-through at McDonald's. I order a kid's Happy Meal because I can only eat a child's portion. But I tell them to keep the toy prize."

GUTSY Gloria Samuels entertains Desert Storm soldiers in the Persian Gulf. 1991

Gloria used to work in sideshows and carnivals to earn a living. Friends urged her to try stand-up comedy about three years ago — and she was an instant hit. Wisecracking Gloria has opened for Little Richard and even toured with La Toya Jackson during the Persian Gulf war. Audiences love her.

Ray Bishop — owner of the LA Cabaret Comedy Club in Encino, Calif., where Gloria often performs — said: "Gloria may be America's smallest comic, but she sure gets the biggest laughs!"

— RICK SANDACK

SUCCESSFUL BUSINESS

Women in Business

Bedow breaks the mold

She builds success in hard-hat world

By ANDY LINGWALL
Successful Business Staff Writer

OWATONNA, Minn. — The construction industry is not traditionally known as a female-oriented trade. It evokes images of hard-hat-wearing tough guys who enjoy their beer after work.

Sally Bedow, owner of Mosier Construction Co., may don the hard hat, but she's no guy.

Bedow, 44, took over Mosier this year after eight years with the Owatonna-based operation. She said she still enjoys people's reactions when career talk comes up.

"I used to be tempted to tell them I drive heavy equipment," Bedow said.

"But as the company's grown, reactions have been very positive. More and more women work in construction these days."

Bedow said people used to expect to see male company owners sweating in the ditch with their crew. But that's changing.

The 25-year Owatonna native said that

See MOSIER Page 15

Successful Business Photo by Andy Lingwall

Mosier Construction Co. owner Sally Bedow finalizes a bid with foreman Dennis Johnson. The Owatonna, Minn.-based operation is currently finishing a 2,400 square-foot addition to the Waseca Area Memorial Hospital and laying curbs and gutters for the city of Owatonna.

SPECIAL SECTION

MOSIER: Bedow discovers opportunities

Continued from Page 13

now, ownership has drifted from on-site work to increasingly administrative duties.

"I don't think you have to be male or female to do any job," she said. "It just takes willingness and desire."

Bedow added that she never asks her all-male crew to do anything she wouldn't do herself.

"I'll finish concrete and do girder work," Bedow said. "I don't do these things often, but I'm willing."

In 1982, Bedow signed on as a secretary with Mosier and learned the ropes under the guidance of then-owner Roy Mosier. From 1985 to 1986 she traveled nights to Dunwoody Institute in Minneapolis to learn blueprint reading and commercial construction estimating. Through the late 1980s, Bedow rose within the company. Her increased management responsibilities, combined with Mosier injuring his back, led to talks of partnership between the two in 1987.

In 1988, Mosier decided to leave the business entirely. Ownership agreements were finalized last January, placing Bedow at the helm of Mosier Construction Co.

Founded in 1975, Mosier specializes in industrial and commercial work.

Current projects include a 2,400 square-foot addition to the Waseca Area Memorial Hospital and an extensive curb-and-gutter renovation for the city of Owatonna.

Mosier Construction just finished building Senior Place, a 10,000 square-foot senior citizens' facility in Owatonna, and 10,000-square-feet of Owatonna city office space, located in the West Hills Complex.

Bedow has unearthed unique opportunities in her business. Since Mosier Construction Co. is female-owned, it now qualifies as a "minority-owned business." Bedow is using this status to become a certified minority subcontractor, which qualifies her company to bid on various state projects, including Department of Transportation contracts.

As a part of Minnesota's Affirmative Action plan, general contractors for state projects must hire a certain percentage of minority subcontractors for the work.

Mosier Construction Co. operates at 511 Cedar Avenue North, Owatonna.

Bedow said women interested in the construction industry may find out more about it by calling Women in Construction. The association helps identify job and networking opportunities for women in the business.

The phone number is (612) 647-9961.

Club Roundup, D-2
About People, D-3

D

Little People is big aid to dwarfs

■ Little People tries to counter the stigmatization dwarfs are subjected to. The group also supports the parents, most of whom are average size.

By Mike Barenti
Idaho Falls Post-Register

IDAHO FALLS, Idaho - Betty Jacobsen felt guilty for months after her son, Adam, was born.

He was healthy and she knew he would eventually grow up and have a fine life. But she couldn't stop thinking about the genetic difference that meant Adam's bones would not grow like other people's bones. Adam would never be 6-foot-4 like his father.

"I felt guilty that I was upset because Adam was a dwarf," Jacobsen said. Until he was about 10 months old, she kept wondering about things like: "How's he going to ride a bike?" But Adam can ride a bike, and play baseball and roller hockey and do just about anything else an 11-year-old boy does.

After Jacobsen got over her guilt, she began looking for information about dwarfism. She found Little People of America. The group, set up in 1957, is designed to educate the public about Little People, said Shannon Carstens, an Idaho Falls resident. She goes to schools around the area to talk about people like herself and shows videos and slides. Most people just don't know much about it, she said.

"It's not that the public's cruel," he said. "They just don't know."

Dwarf Rob Fille

About 50 members of Little People of America from Idaho, Utah, Washington and Oregon recently met in Idaho Fall. "It's just a get-together," said Carstens, who runs Carstens' Bakery with her husband. The group has 5,000 members nationwide.

But there's more to the meeting than just giving people a chance to socialize. They want to dispel the side-show stigma Little People often live with, said Rob Fille, the district director and a computer-aided drafting technician who works for the Navy in Bangor, Wash. "It's been a stereotype that's been on us for centuries," he said.

Fille said he has faced discrimination all his life because of his size. Junior High School was one of the worst times, he said. But his size also has cost him jobs, and even now, co-workers will often do things like have conversations other over the top of his head, as if he wasn't there. "It's not that the public's cruel," he said. "They just don't know."

There are roughly 25,000 Little People in the United States, Fille said. Some are dwarfs, meaning their bones grow differently than what is considered normal. There are 250 different types of dwarfs, he said. Those sometimes referred to as midgets have a problem with their pituitary gland, so they do not grow as big as the average person, Carstens said.

About 80 percent of dwarfs are born to average-sized parents, Jacobsen said. One of the most important things Little People of America does is help those parents. "It is very traumatic — I know it was for us," she said.

Jacobsen shares what she has learned helping Adam with other parents. She also learns what's worked for other parents. "There's no point in re-inventing the wheel," she said.

bring back bikinis.

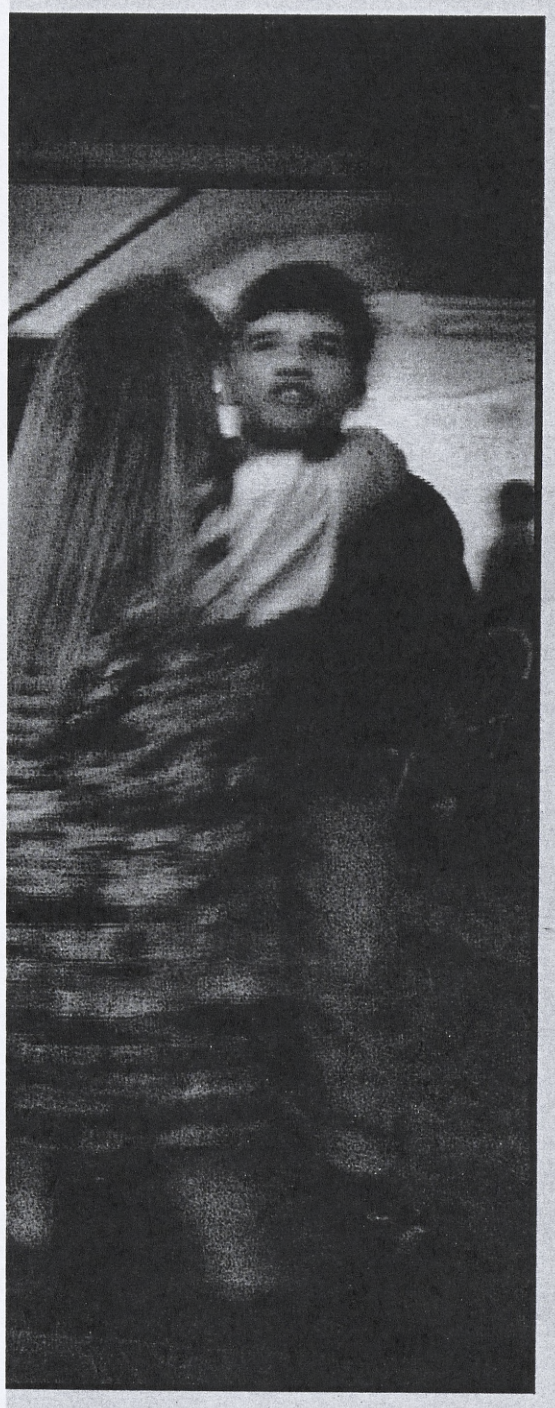
Speaking Freely: Conquering the Fear of Making a Speech

WEST

Eye to eye, heart to heart

When the Little People of America gathered for a convention, some found love, others friendship, and still others found themselves.

SAN JOSE MERCURY NEWS / FEBRUARY 14, 1993



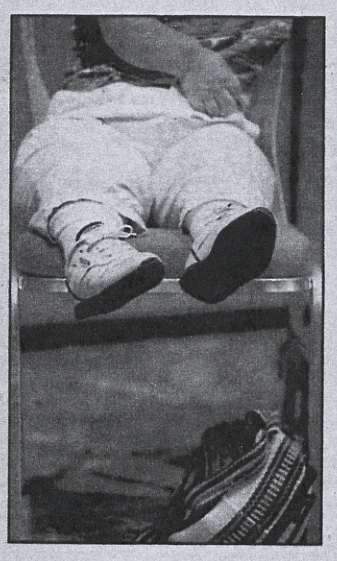
ABOVE: A dance concluded the convention held by the Little People of America in San Francisco last summer. LEFT: The convention celebrated the diversity of its participants. RIGHT: The obstacles faced by some participants is dramatized by the difficulty Julie Rotta has in handling even a standard-size chair.

By John Wolin
Photography by Gary Parker

Both Great & Small

THE HOTEL STAFF HAD BEEN WELL-briefed and reacted with poise, as if having 500 or so dwarfs as guests was an everyday occurrence. Some of the guests found fiberglass milk crates in their bathrooms—something to stand on so they could reach the sink.

A set of bleacher-like stairs, the kind you usually see next to stages, had been rolled in front of the registration desk. A woman from California stood on the top step, bringing her eye to eye with the clerk.



When my turn came, I stayed put, at ground level. I'm not sure why. Maybe because much of my life is spent craning, and I always have managed to make myself understood. Maybe I didn't want to crowd the woman on the top step.

Maybe I wasn't ready to become just another dwarf.

Pam Prentice, the woman on the top step, followed me to my room, chatting enthusiastically along the way, almost hyper as she introduced me to what became a numbing number of other dwarfs. I knew Pam only because she advertises her exercise video in the Little People of America's national newsletter and I had called, seeking not the video, but a contact, a friend to guide me through this immersion.

For five days in a hotel on San Francisco Bay this summer, I became part of a world I had always avoided. Those first minutes, I was a stranger among my own people.

Pam and I reached my room without benefit of the rug-covered box in front of the elevator buttons. I rested on one elbow on the edge of the bed, humbled and bewildered by the uncertainty of the days to come.

The shortness of Pam's legs drew her to the front of a cushioned chair, where her knees could bend so her feet wouldn't stick straight out like little Edith Ann's in Lily Tomlin's old "Laugh In" skits. Pam was much quieter now. She sensed my unease. She was years, a lifetime of self-acceptance, ahead of me.

"You know, you're tall," she said.

The tangent streaked not just out of the blue, but out of any reality as I knew it.

I am 4 feet 7 inches tall, which is not tall at all. Yet she was right. Downstairs, there had been hundreds shorter, some much, much shorter. Where I have needed help reaching cereal boxes high on grocery shelves, their own kitchen counters are in a no-man's-land somewhere over their heads.

"And you're handsome," she said.

I was somewhat embarrassed and buoyed not at all. I wanted to flirt back. I found her pretty, kind, bright. But I couldn't. I needed a few minutes alone. I wanted her to leave. I wanted to postpone, just for a few minutes, what lay ahead.

Downstairs, I would be a first-timer seeking acceptance, yet not quite sure I wanted it. I would, at age 45, learn that these strangers knew my needs and fears better than my best friends. Downstairs, in the lobby and dozens of meeting rooms, were gathered my people—people who in the next five days would unconsciously teach me things about myself that I will need years to fully absorb.

THE FIRST GLIMPSE OF THE BUFFET TABLE for the opening-night supper forces us to stare, then snicker, a smile crossing every face. In a misguided effort to make things "accessible" to its convention of dwarfs, the hotel management has gone ab-

surdly underboard. Dressed in heavy white cotton, laden from end to end with hamburgers, hot dogs and the rest of the necessities for a picnic, the table appears to have had its legs knocked from beneath it and bears its load a foot, perhaps a few inches more, off the floor.

Parents hustle after the youngest of the children, who want nothing more than to crawl onto a platter of sliced tomatoes. Most of us have to bend over—a most unusual experience—to reach our food. It would be amusing, the irony of ironies, were it not for the fact that so many of us sit high above the food in wheelchairs and others have had our spines fused and cannot bend at all.

My confreres react with a dignity that dwarfs the situation. There is no embarrassment, no thought that someone has pulled a cruel joke. There is no panic, no anger, none of the angst that surely would blossom were a more traditional group of human beings to face a similar inconvenience. We are, if nothing else, emotionally flexible.

Seeing us all in one room, seeing now perhaps really for the first time the individuals that blurred past when I arrived just hours ago, I am bolstered by our many differences. Get past the fact that we are all fairly short or very short or inconceivably short, and we are as different, as distinct one from another as are the Lions or the Elks or—to carry it to an extreme—the Democrats.

To my right, a young man shares the horrors of custom-made shirts that aren't custom-made at all, but rather custom-assembled of ready-made pieces, once leaving him with his pocket tucked into his pants. A bit beyond, Israeli politics and German technology are debated. And to my left, Pam demonstrates one of the great advantages of being short: Knee-highs serve as her stockings, leaving friends and co-workers jealous over the number of patterns she finds.

Many of us are in wheelchairs, or on electric scooters, implements necessary because our dwarfism has misshapen our spines, robbing our legs, and sometimes arms, of their strength. Most of the wheelchairs speak of permanence. They are Winnebago-like with bumper stickers and orange reflectors, a pair of crutches and an oxygen bottle, a purse and even a cellular phone stowed just so.

On the way to the ballroom, even struggling down the corridor on two canes, I had easily passed a woman half my height, walking with the aid of a cane no longer than a maestro's baton. I cannot help but imagine how much time and energy she expends just getting from place to place. I will see her time and again, but I will never see her smile.

We have split ourselves off more or less by age, leisure suits at one table, T-shirts and jeans at another, Izods and button-downs moving between. Little People of America was founded by movie and television actor Billy Barty in 1957 as Midgets of America. He is here, sitting with his peers, but almost always also cocooned by children who love to gather at his side.

Much besides the name has changed. Entertainers like Barty are rare among us tonight. We are lawyers, teachers, engineers and other professionals. The circus is behind us, notwithstanding the full-page ad in the LPA newsletter recruiting dwarf stunt persons, actors and acrobats for a new George Lucas movie.

Many of us are involved in making sure those like us and unlike us get an even break.

Tonight's opening speech will be given by Deborah Morris, a young woman in a blue suit, Betty Boop earrings as her accessory. Her subject: the Americans With Disabilities Act, a body of law that provides the hope of equal opportunity for many in the room. Morris and other LPA members worked for the ADA's development and passage. But in a speech that draws from Martin Luther King Jr. and Abraham Lincoln, she will point out that the ADA itself discriminates by aiming most of its protection at those in wheelchairs. Largely forgotten are the limitations and needs inherent when everything in your world is designed for someone with a body twice as large.

Morris opens an old wound: Should those of us who are short—and understand that I am talking about people who at maturity may be only 2 or 3 feet tall—yet in no way crippled, consider ourselves disabled? It is a question that goes unanswered.

Later in the week, when a woman attorney who also is a dwarf explains that buses in some cities won't lower their wheelchair platforms to pick up a short person—though that person can sometimes barely see over the first step and would have to be a mountain climber to approach it—I find myself hurt and angry.

Still, I know that for so many in this room, the real handicap is the limitation imposed by some form of paralysis. My own life could not have changed more when the narrowness of my spine finally took its toll and I lost all but minimal strength in my legs at age 21. I can no longer jump to knock a sweater off a high shelf, though I do have a cane that I can hook it with.

"MY CONFRERES REACT WITH A DIGNITY THAT DWARFS THE SITUATION. WE ARE, IF NOTHING ELSE, EMOTIONALLY FLEXIBLE."

Actor Billy Barty, founder of Little People of America, talks with Cheryl Murphy, 13.

For much of my life, being a dwarf has been entwined with paralysis. I knew, of course, that many dwarfs did not suffer from spinal damage.

In theory.

The fact was a shock: dozens of men and women my size walking with ease and grace. I do not walk around envying people of standard height. I feel different, not lesser. But here among people that—in some cases—I tower above, I feel that sharp ache of desire. I want what they have: healthy arms and legs. The Dwarf Athletic Association of America is holding its national games in conjunction with the convention. Sports is my specialty. Yet I do not attend a single event, not even the championship basketball game.

BETH TATMAN MIGHT BE THE LAST PERson you'd imagine leading "IS THERE A SEXUAL PROBLEM? An Open Forum About LP Sex (open to 13 and older only)."

Tatman is confined to a mechanized wheelchair and appears uncomfortable, body parts rolled one on top of another. Life has not been kind: Metal rods support her spine and other brittle bones; her husband died several

The hotel supplied plastic milk crates for conferees, such as Laureen Zeno, to use as stepping stools.

years ago.

Yet Tatman is exactly who this audience of a couple of hundred in a hotel meeting room needs as a guide and mentor—someone who cannot just roll in and out of the hay without effort, someone who will never, ever, under any circumstances, be able to do it in a airplane restroom and then write Penthouse about the experience.

Many of us have trouble coupling. We may not fit together. Our limbs may be too short or too rigid to bend around our partner's. We may not be able to reach. Because of the spinal cord damage many of us suffer, we may have trouble with erections, or having achieved one, may find orgasm a guest with a mind of its own, appearing rarely, if ever, when desired. "Are you a member of the Dead Pecker Club or of the Dying Pecker Club?" Tatman will ask.

Tatman understands. More so, the anecdotes she shares let those in the room know they are not alone. It is not a matter of misery loving company, but of knowing that there are concrete reasons for the misery.

In the mid-'70s, Tatman began attending sexuality seminars for women of short stature —given, unfortunately, by male doctors of average height.

"Once, at Johns Hopkins, this pediatrician passed out a vibrator and other goodies and we passed them around like hot potatoes, everyone was so afraid to hold them," Tatman begins.

"He showed slides of people getting into every position in the world. I raised my hand and said, 'I have six steel rods in my body. If I got into one of these positions, we'd need a blowtorch to get me out.'

"That doctor's slides do not apply to us."

In the years that followed, in addition to serving Little People of America in more conventional roles, Beth Tatman became the camp counselor, the mother confessor, cutting away the mysteries and angst of sex among little people.

"There are a large number of people here who have not had any sexual activity at all," Tatman tells us. "Many in this organization have been married 10, 15 years or longer and have not consummated their marriage. They were not able to. That does not mean they do not love each other very much. Many are fully satisfied."

Now with a firm grip on her audience, Tatman turns her attention to the young people and in doing so draws me back to my own youth. There was very little dating. During the age when the shirt has to be the perfect pinstripe and the shoes just so, there is little desire to date a dwarf. The teen-age years are a difficult time to be different.

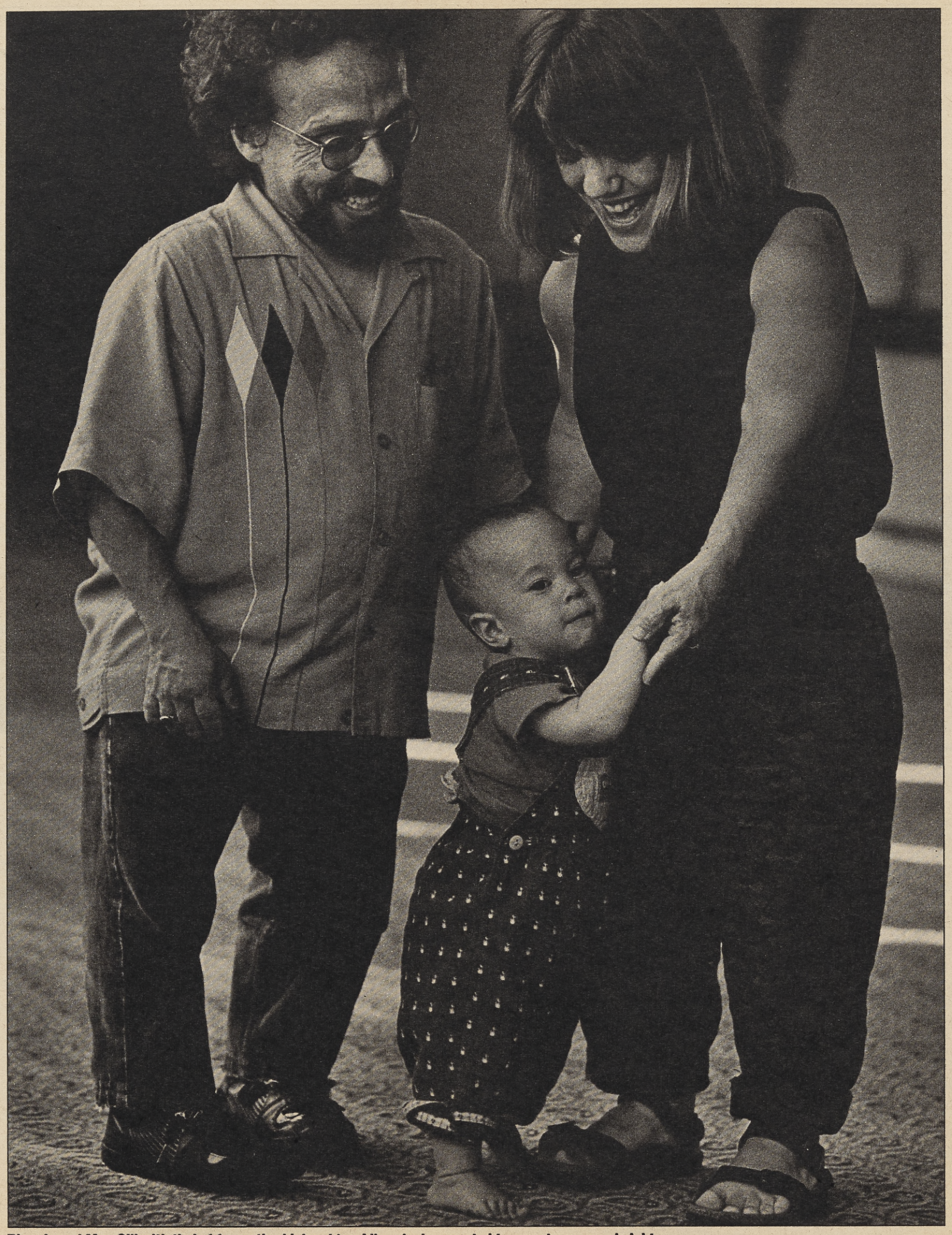
"Much of the dwarf population missed the years the basic ground rules were learned," Tatman is saying. "We're naive. We never leaned over in a movie and gently let a hand fall onto a breast."

She pauses. "First, we likely don't have the date. Second, our arms aren't long enough."

I lost my virginity the summer after graduating from high school in a whorehouse in Guatemala City, and as a young working man would satisfy my needs through the "day rate" offered by the hookers down the hall in my apartment building. My only other choice was unleavened frustration, and loneliness.

I never truly made love until I got married.

"We can't just ask out two or three people



Ricardo and Meg Gill with their 11-month-old daughter, Lily, who is expected to grow to average height.

and get a date," Tatman says. "The singles bars are full of average-size attractive men with no limitations who are shot down night after night, but eventually they find a girl."

We don't. Not when we're the only dwarf in the room.

Hence, one of the dangers of this convention. There are dwarfs all over the place. Young, single, eligible, horny dwarfs. Dwarf men who haven't quite learned how to flirt. Dwarf women on the way to the every-evening dance in miniskirts stretched tight and about one millimeter below outrageous.

Suddenly, the playing field is evened. For every young dwarf man who has spent the past year alone there is a dwarf woman who has endured similar frustrations. For every dwarf tired of being forever alone, the chance to find a mate has arrived, neatly packaged in a one-week hiatus.

So what's the problem? It's too easy to fall in love.

It's as if you're on a cruise and have met a very nice person from West Hempstead, N.Y., and for six days and five nights cannot think of anyone else.

Except that on a cruise, when Partner A returns to West Hempstead and you return to your burg, that's likely the end of it. There may be the occasional card and it may take a while for the image of Miss West Hempstead to disappear, but soon it will, among all your other friends and suitors.

It's different with us. In many other cases, there are fewer other friends back home. And in all but the rarest cases, there are no other suitors.

"Be careful with your expectations. People have waited a whole year to meet their mate," Ronald Piro, one of two speakers, announces at a seminar for first-time conventioneers. "More times than not, they go home disappointed."

As much as we may want to think that the only barrier to love has been our stature, the reality is that for dwarfs, as for any people, making a good match is a rare accomplishment. Piro and others will warn that these conventions are famous for one-week courtships, nurtured with maid service, meals out, and a ready-made social schedule. Back in the real world, the pairings evaporate, no matter how desperately the lovers wish they might last.

I understand the emotion that creates instant couples. For much of my life I feared —and fear doesn't really do justice to the brutal emotion I felt—that I would never be married. Lack of a mate, lack of a partner in life, can make other problems seem trivial by comparison. Loneliness can be the most chilling prospect of all, the one that challenges even our will to live.

THE YOUNG MAN, A COLLEGE FRESHMAN, has his arm around his sister's back. Unlike her brother, who comes up to her shoulder, she is of average size, a Boston University graduate student whose master's thesis will examine how the disabled are perceived. She could have been many places with many people this summer week, but is here with her brother.

There are so many parents and brothers and sisters here, whole families sitting vacation-like in the restaurant. Usually in the middle somewhere, there will be a child who sits lower than anyone else, one head far below the others.

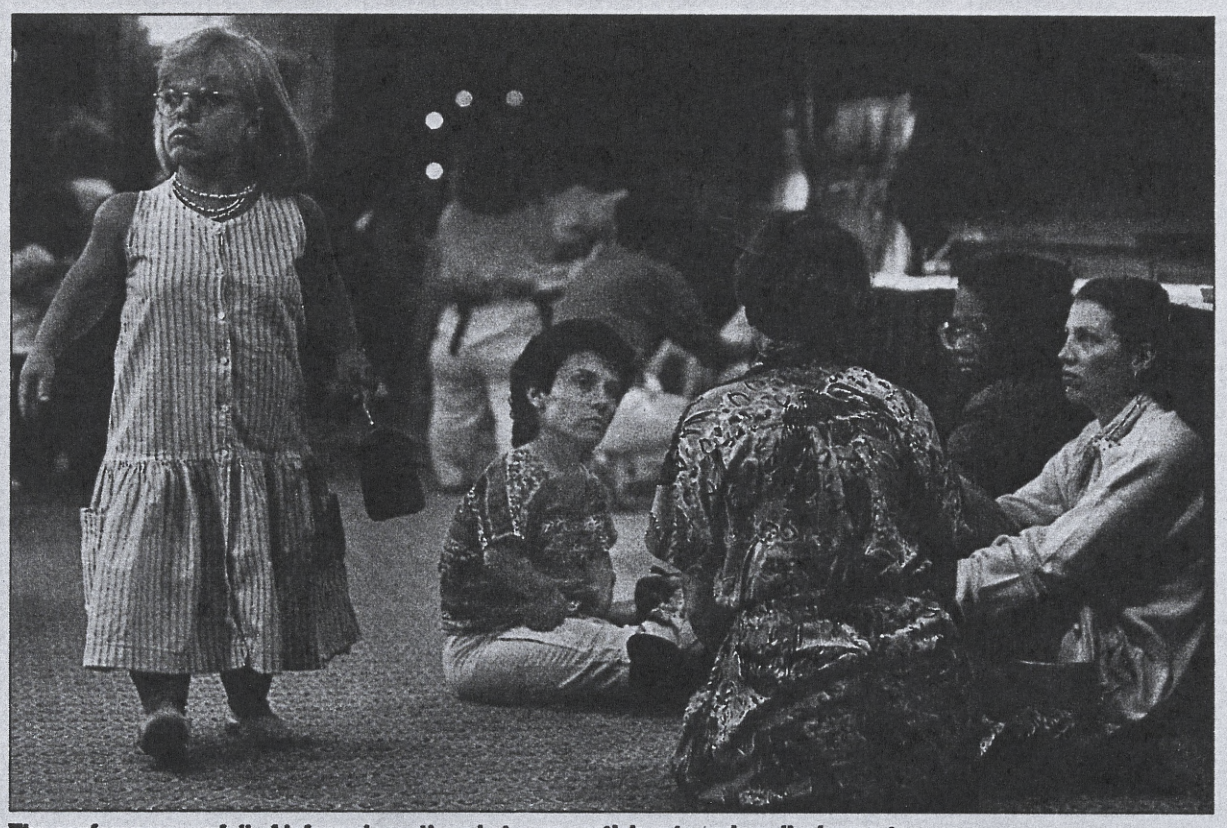
I know that bond, because I have such parents, and such a brother and sister. Many years ago, in an attempt to make me taller, to stretch me, my own brother and sister had held me by the feet and tugged as I gripped, belly on the floor, the legs of a chest of drawers.

One morning early in the week, during a welcoming tea for the LPA medical staff, I sat in the corner of an overcrowded hotel suite with a father 6 feet, 4 inches tall, his 5-foot-10-inch wife and their 3-year-old son, Danny, an achondroplastic dwarf.

There were so many people in the room and it was so hot that the father sought refuge under an air conditioning outlet, a stream of sweat staining the front of his polo shirt. His rough-and-tumble son cavorted like any other child his age, sprinting with the finesse of a bumper car from one end of the room to the other, disappearing between legs and under furniture. His smile was a beacon of joy.

Danny has had a difficult time. In addition to being short, with legs that threaten to bow, his head is larger than it should be because cranial fluid doesn't drain normally. In February 1991, a shunt was inserted into the upper right side of his skull and a check valve was hidden beneath the scalp near his ear, with a drain about the size of a pencil extending from there to his stomach. The plumbing keeps his head from swelling any further. The hope is that as he matures, the proportions will match up.

I listened with growing astonishment as the father talked about the day his son was born: "We were told about it in the wrong way. The staff pediatrician said, 'It seems we're the proud owners of something just short of a



The conference was full of informal meetings between participants and medical experts.

"I UNDERSTAND THE EMOTION THAT CREATES INSTANT COUPLES. FOR MUCH OF MY LIFE I FEARED THAT I WOULD NEVER BE MARRIED."

circus act.' "

I would like to say that his story is an obvious exaggeration, extreme beyond belief. But I have heard too many stories like it.

A few minutes later, another very tall woman passed by and stared for a few seconds at the couple and their child, examining all three.

"My husband is 6 feet 4 inches and I'm 6 feet 1," she barked. "Don't let anyone tell you your height won't affect him. My daughter is 4 feet 1 and just 9 and a lot taller than some of them around here."

Some of them around here. From the mother of a dwarf, the mother of one of them. A bit of the real world had sneaked into the sanctuary, a woman cocky because her kid is the tallest midget.

THE ADULTS ARE MOSTLY IGnoring the platter of fruit, but the strawberries especially have the full attention of two little girls who move from the end table to their parents as if guided by a track. Tricia, 6, could be my own child, for we have a gene in common. I am sitting next to her father and she backs up against my knees, making it plain she wants to eat her strawberries sitting on my lap, head thrown back against my chest as if overcome by a monstrously funny thought.

Of all the emotions I will feel this week, the love she allows me is the most pure, the most simple. I am truly touched by this child, rescued at 20 months from foster care in Korea, where she had been given up by her natural parents when less than a year old.

Tricia has a sister, Lauren, nine months older, the natural child of Tricia's adopted parents. Both girls are achondroplastic dwarfs.

"At first I said, OK, let's give her an injection, let's get her well," the father said of the moments after Lauren's birth. Later, "all I wanted to know was would she have a normal life span and normal intelligence. . . . The 'Yes' brought tremendous relief."

In the months and years that have followed the child's birth, the mother and father have immersed themselves in the world Lauren brought them. Tricia was adopted in part for "help, love and support for our daughter." And if you speak to the mother, and ask if she ever thinks about how different her adopted daughter's life might have been, about how much she has given that child, she will answer that it is Tricia who gives.

The mother writes, edits and publishes a newsletter for families of dwarfs that informs on subjects as critical as the continuing misdiagnoses of dwarfs, both their types and problems, and as basic as learning how to protect a dwarf child so small that it might bump its head on the bathtub faucet.

After three years of a Montessori education, the two girls entered public school this fall. The meetings the mother had with administrators and teachers touched on every detail. Though the goal was to begin mainstreaming, there had to be concessions.

Tricia and Lauren need to sit on the floor and remove their panties before crawling up onto a toilet. There is no need to expose them to a floor covered with the pee from poor-aiming little boys.

They use the teachers' restroom and have a small bench in there to sit on. They have been adopted by many and protected.

IT IS ALMOST MIDNIGHT AND NO ONE SLEEPS. The very youngest children dance, sometimes alone, a whirl on the floor, sometimes together, and sometimes in the arms of their parents.

They are bathed in the blue lights. One mother is on her knees, yet her child still comes up only to her breasts as she dances in her mother's shadow like a windup toy. Her

Astri Solaas of Norway and Samuel Roloff of San Francisco share the hours before her departure.

"THE SEMINARS ARE OVER. WE ARE HERE TO DANCE. AND SOME OF US ARE HERE TO MATE, OR TO GET AS CLOSE TO MATING AS POSSIBLE."

father, a tall energetic man, moves slowly from foot to foot with his older daughter cradled in his arms.

Taped music blares from speakers that more than ever seem oversize. A young man surrounded by lights as loud as the music adds to the pandemonium, a convulsing dee-jay shouting commands to those massed on the floor.

The seminars are over. The side trips to a national park and the national pastime are over. We are here to dance. And some of us are here to mate, or to get as close to mating as possible. The bodies on the floor have trouble keeping up with what the mind wants to do. But even terribly contorted bodies show no hesitation in trying. One man spins in the seat of his motorized scooter, like you may have as a child at a lunch counter, and I wonder if I could ever be that brave, that unafraid.

My moment comes when a woman from New York suggests we dance. The music is slow, something out of the 1960s and the emotion I feel as her warm cheek rests next to mine has nothing to do with my wife and child at home, nothing to do with true romance. What is has to do with is the overwhelming power of a realization:

Never before have I danced with a woman cheek to cheek.

SO I'M SHORT AND I HAVen't hung around much with people like me. It's something I never had to explain before. But there was a certain curiosity at the convention, a certain curiosity at home, both in the days of anticipation and after I returned home.

At the convention, it reached a point of concern that maybe I had been avoiding something—them, me, us, something.

And by having married a woman of average size, I had married outside of my own, and had thus in some way been a traitor. No one ever said as much, but there were questions that began leading in that direction, tilts of the head in a tsk-tsk sort of way as others got to know me.

When I was in junior and senior high, I knew another dwarf, a hurt man confined to a wheelchair. He was one of the first people to point me in the direction of the surgeons at Johns Hopkins Hospital—a kindness which, in some sense, means I owe him my arms and my legs.

We share many pains, disabilities and frustrations, but we hardly know each other. I have been to his house, but have never invited his family to mine. I do not believe that in all the years we have known each other we have ever had a decent conversation. Though I respect his courage from afar—he and his wife have adopted two dwarf children and are providing love and a home for children who sometimes go unwanted—I have no strong desire to begin a friendship some might feel is overdue.

Why? I have never wanted to allow my life to be dictated by my stature, or lack of it. A mother of a dwarf at the convention said over lunch one day that as much as she understood the challenges being faced by those around her, she could not be friends with everyone simply because they, like her son, were dwarfs: "We aren't," she said, "going to be friends because of a gene."

I understood what she meant and I knew she meant neither harm nor disparagement. It's just that when one is different, when what you are has the ability to determine who you are, there is an urge to resist.

But by midway through the convention, I had to wonder if in my urge to stand on my own—to resist the isolation I feared "special treatment" would bring—I had not missed something important. I have black and white friends, male and female friends, friends who first spoke other languages, friends who are both happy and gay. Yet until San Francisco, until being befriended by people more like me than I knew, I had very few short friends.

At the end of the week, we are called together for a group picture, to be shot outside the hotel, photographers standing on the roof. A woman attorney from the Northeast walks quickly the other way, as if trying to flee a family fight.

I have yet to see her smile. I am told she hates being here, that she hates being one of us, hates every part of the social experience. I wonder how close I have come to being like her.

The sun shines brightly, the wind grabbing at us as it dances off San Francisco Bay. I stand with hundreds of other dwarfs as the hotel's bellhops try to help the photographer get everyone into the picture.

As I watched the attorney rapidly recede, I learned something new. To not be here would be to deny my own existence. W

JOHN WOLIN is a reporter for the Miami Herald.

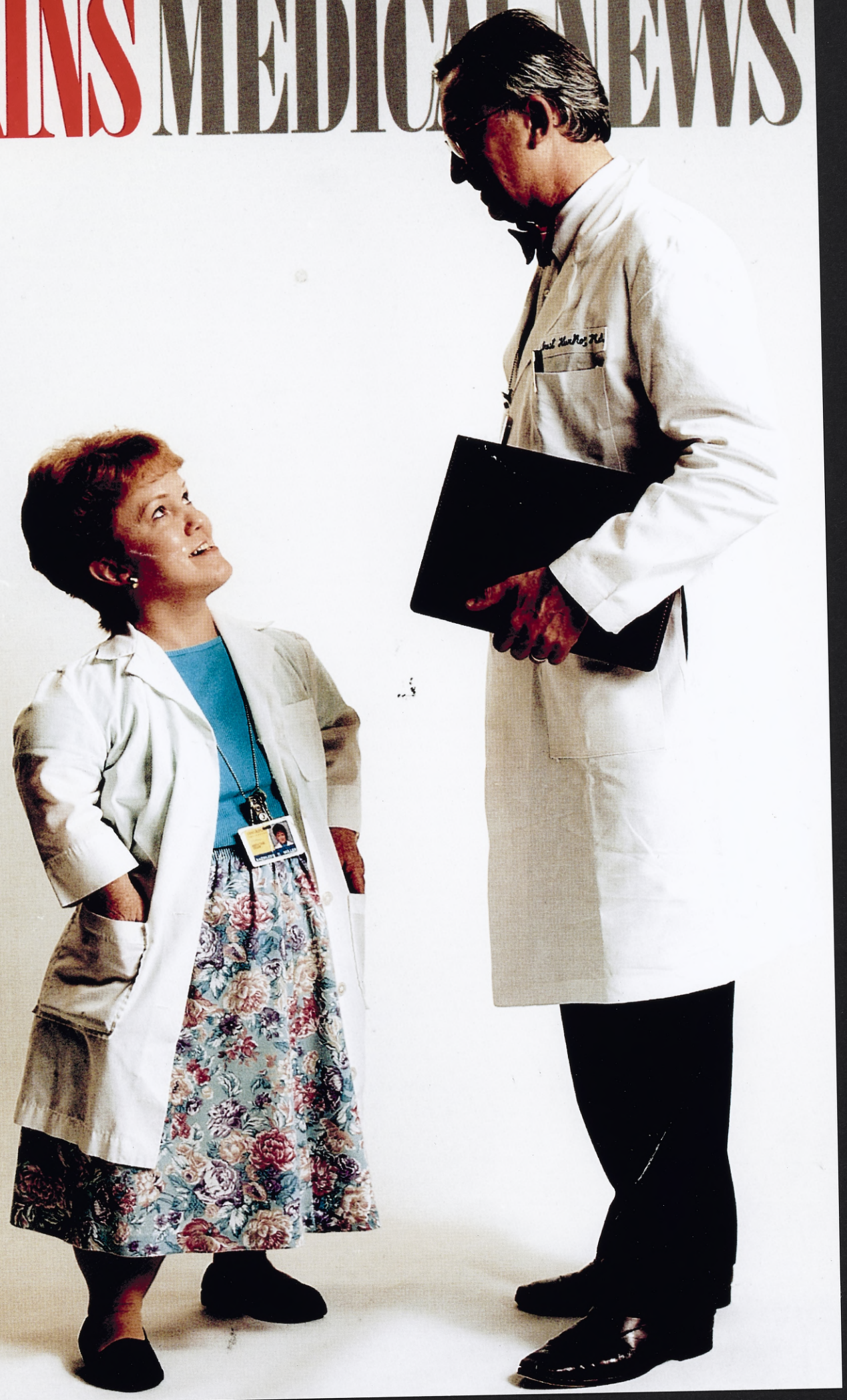
The more than 500 people who gathered for the convention had only this in common: their size and their quest for dignity.

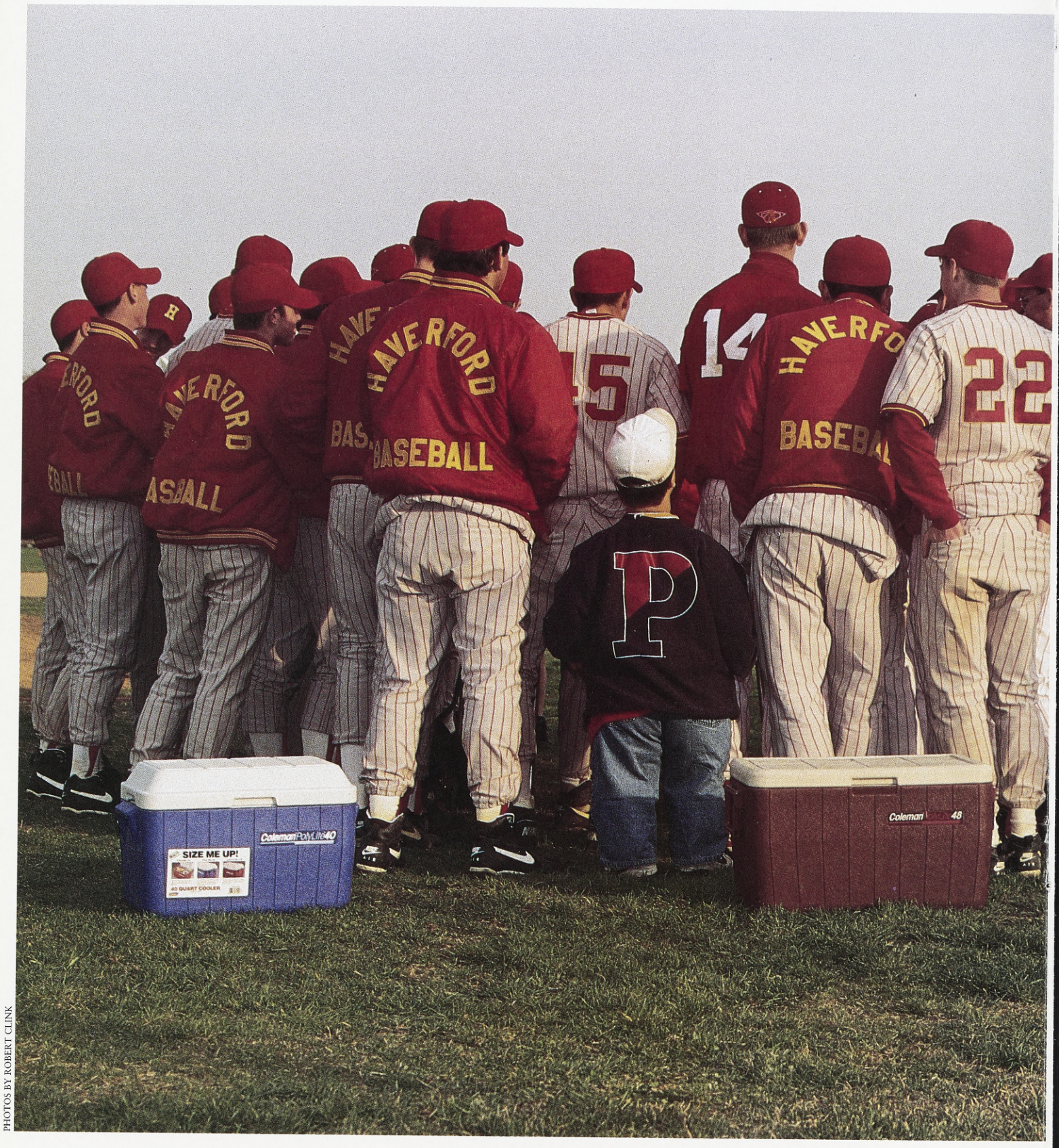
HOPKINS MEDICAL NEWS

LIFE AS A LITTLE PERSON

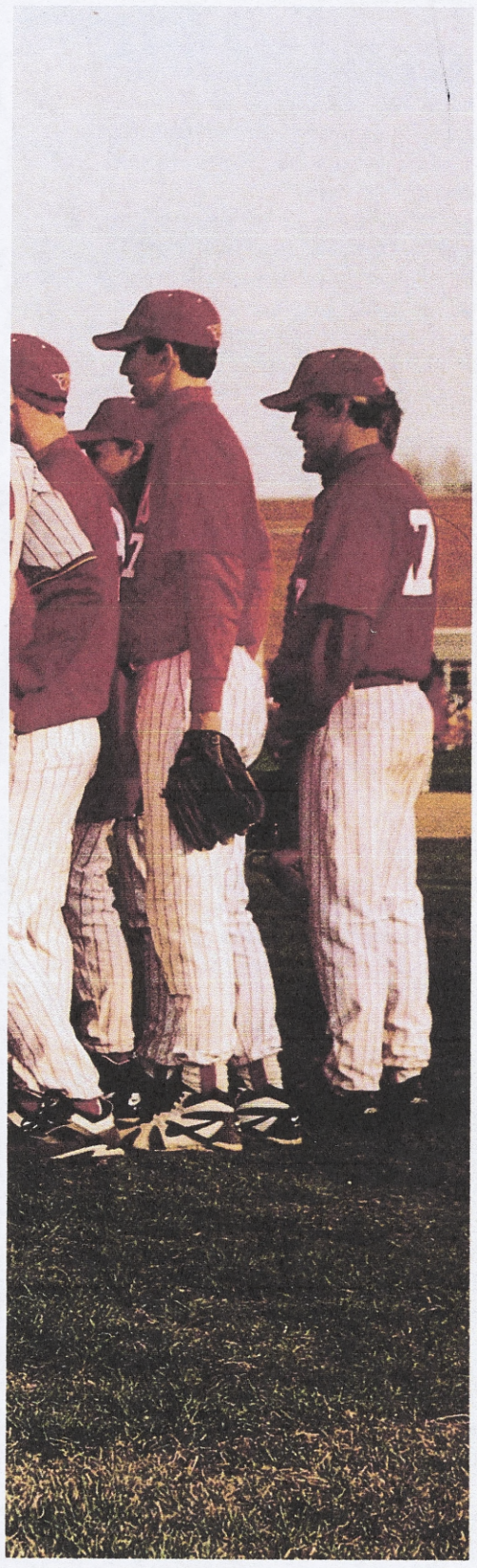
In spite of all the difficulties of dwarfism, new ways of dealing with the condition are helping patients handle life with pride and a sense of self-worth.

THE LONG ROAD TO THE M.D./PH.D.





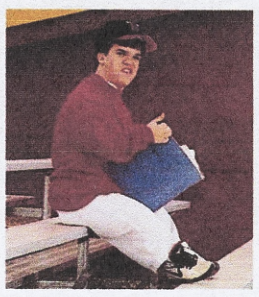
PHOTOS BY ROBERT CLINK



Increasing activism, blunt-speaking role models and impressive medical advances are allowing the short of stature to live healthier, happier lives.

Life as a Little Person

By Randi Henderson and Marjorie Centofanti



Kevin Leitzell is sports editor of the school paper and manager of the baseball team.

In nearly every room of Kevin Leitzell's house on a shady street in suburban Philadelphia sits a footstool. Dangling from the light switches are long plastic rods, and the lock on the back door measures inches lower than on most doors. Parked in the driveway is Kevin's '94 Ford Escort, and if you peek through the window you'll see extensions on the pedals that elevate the surfaces more than a foot.

At 17, Kevin is a junior at Haverford Township Senior High and stands an even 4 feet tall. He is an achondroplastic dwarf who uses footstools, pedal extensions and the like to compensate for his short stature. He's also sports editor of the school paper, manager of both the soccer and baseball teams, and working on getting a date for the prom. There is nothing in the demeanor of this young man, who hopes for a career in radio broadcasting or sports reporting, to indicate that he will allow his short limbs or any of the host of other physical problems that can accompany achondroplasia to limit his ambitions.

On this day, Kevin greets a visitor with a friendly smile. "My attitude toward the world," he explains, in answer to a question about everyday difficulties, "is like it or not, here I come!"

It's an outlook that has been nourished and supported by the Johns Hopkins Center for Medical Genetics, where Kevin, since he was a year old, has been one of hundreds of people of short stature who receives treatment. For years, Hopkins offered the only coordinated, interdisciplinary approach to care for dwarfs in the country. With the addition three years ago of its Kathryn and Alan C. Greenberg Center, specializing in research, teaching and treatment of skeletal dysplasia, today it is recognized as one of the world's premier facilities for medical problems associated with dwarfism.

ROBERT CLINK

Kevin Leitzell and fellow sportscasters on the air at Haverford High School's radio station.

The Center for Medical Genetics evolved out of the division of medical genetics, founded in 1957 by Victor McKusick, M.D., who even then was well on his way to becoming one of the world's foremost geneticists. A major force behind the Human Genome Project and editor of *Mendelian Inheritance in Man,* the human geneticists' Bible, McKusick is an authority on genetic diseases of connective tissue, many of which result in short stature. Through the years, these patients increasingly have come to Hopkins, first for McKusick's expertise and later to be seen by the bright team of specialists he had assembled, who were providing an array of services and innovative therapies.

Most achondroplastic children come as surprises to their average-stature parents. That was the case when Cindy Leitzell gave birth to Kevin 17 years ago.

A Diversity of Clinical Problems

Dwarfism is the general classification for literally hundreds of conditions characterized by short stature, but which beyond that display a wide diversity of clinical features. In addition to the orthopedic problems caused by their stunted bone growth, little people are apt to need special treatment for neurological, otolaryngological, respiratory, dental, vision, nutritional and gynecological problems complicated by dwarfism.

Diagnosis is an early priority when new patients are seen at the Center, and the decades that McKusick and his proteges have spent cataloging the various disorders and analyzing family pedigrees help patients and their families learn the realities of their inheritance and the course their conditions could take. Yet diagnoses are often no snap. "Of the 200-plus skeletal dysplasias, only about 100 are well-described," says pediatric geneticist Clair Francomano, M.D., who besides co-directing the Greenberg Center with neurologist Orest Hurko, M.D., serves also as chief of medical genetics at NIH's National Center for Human Genome Research. "The rest become private little syndromes, known only to that patient's family. These patients write their own natural history of the disease."

Adds Francomano: "Some patients can walk into the office and you know immediately by proportion, by their facial characteristics, what they have." For others, she, McKusick and fellow geneticists need an algorithm. If body parts are in proportion, they suspect something endocrine. If they're disproportionate, skeletal dysplasias are more likely. For the patient with shortened limbs, the path branches again: Which part is more affected? The fingers? The feet? Some disorders, like spondyloepiphyseal dysplasia often involve hearing loss; others, such as Stickler's syndrome, produce a very small jaw.

For a rich sampling of the many types of dwarfism, one need look no farther than the walls of the office of Kathleen "Dee" Miller, clinical coordinator of the Greenberg Center and herself an achondroplastic dwarf. Miller, who has become a trusted counselor and friend to many of the little people and their families who pass through the center, has papered her office with their photographs, including many group shots from conventions of the Little People of America that bring people of short stature together.

Formed nearly 40 years ago by 20 original members, the organization had topped 1,000 by its 1989 meeting in Baltimore. At each convention, no matter where it takes place, Hopkins' Greenberg Center now is on hand with a team of specialists to evaluate and diagnosis little people seeking medical services.

Fortunately for diagnosis, the majority of skeletal dysplasias fall into one of four or five types and about half of those with short stature have achondroplasia. Achondroplasia—from the Greek for "without cartilage"—is distinguished by short limbs, a moderately enlarged head, average-size trunk, a flattened nasal bridge, bowed legs, swayback, and the characteristic short-fingered trident-shaped hands, with wide separation between the third and fourth fingers.

An early convention of Little People of America, meeting at Hopkins' Evergreen House, along with several physicians.

Achondroplasia is a genetic disorder, but nearly 80 percent of cases occur from spontaneous gene mutation rather than from direct inheritance, so most achondroplastic children come as surprises to their average-stature parents.

Surprise for Parents

That was the case in 1978 when Cindy Leitzell gave birth to Kevin. Both Cindy and her husband Bob are of average stature; there are no other dwarfs in either of their families.

Kevin was diagnosed at birth, a month premature and in respiratory distress. Bob Leitzell remembers with some bitterness, "The doctor said, 'Your son is not normal and he may never be normal.'" Bob saw the baby and was able to console his wife, who was recovering from a Caesarean section and hadn't yet seen her infant. "He doesn't look so bad," Bob told Cindy. "He's got all his fingers, he's got all his toes, he looks like a normal baby."

In the coming months, as Kevin's development stuttered along and his physical differences became more apparent, the Leitzells worked with their doctors to try to discover the reasons for their baby's persistent failure to thrive. They began to realize they were dealing with a complex pattern of physical abnormalities. "The geneticist we were seeing in Philadelphia kept referring to research done by people at Hopkins," Cindy remembers. She would call Hopkins for the latest information. "Finally we said, 'Hopkins is only two hours away, why are we getting everything secondhand?'"

> Formed nearly 40 years ago by 20 original members, Little People of America had more than 1,000 members by its 1989 meeting in Baltimore.

Battling pneumonias and congestive heart failure, Kevin was evaluated at Hopkins and in and out of the hospital throughout his second year. A sleep study determined that he suffered from apnea—failure to breathe properly as he slept—that starved his tissues of oxygen, leading to his other problems. So, at 15 months, his breathing was assisted with a tracheostomy, and suddenly he began to thrive.

Putting a hole in the trachea may seem an extreme measure to treat a chronic problem, but—as the Leitzells and many parents in similar situations learn—the "trake" is not difficult to maintain with proper training and it often is the only thing that will turn the corner for children whose breathing passages are obstructed by their bone structure.

Breathing problems are common for people with these underlying skeletal differences. Their smaller throats, plus a compromised nervous system, allow children's tongues to ease backward at night, blocking airflow. "Whether it's obvious or not, sleep apnea is serious," says otolaryngologist Bernard Marsh, M.D. "It deprives the brain of oxygen, and can cause long-term changes in the heart and other organs." Sometimes removing tonsils and adenoids is helpful, he adds, "but we wind up doing tracheostomies more often on achondroplastic children than those who aren't."

Like most other achondroplastic dwarfs,

HANDLING HARD CHOICES

When Beth and Kitt May[1] decided to marry after falling in love at an annual convention of the Little People of America, they knew they would be taking a chance in having children.

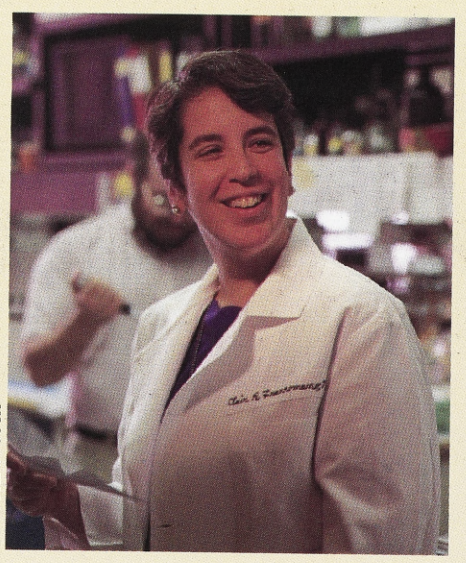
As achondroplastic dwarfs, both carry one normal and one mutant gene for the disorder. So, although an offspring was more likely to be born with the standard form of achondroplasia like themselves, there was also a one-in-four chance that the baby could carry the lethal double dominant mutant achondroplasia gene. In that case, every problem that goes with achondroplasia would be horribly intensified. No child with this form of the disorder has ever survived longer than two years.

For the first time, however, achondroplastic couples like the Mays can approach childbearing in a more enlightened way. This past year, using research done at Hopkins by geneticist Clair Francomano, M.D., and colleagues, California scientist John Wasmuth located the gene for achondroplasia.

Wasmuth, who'd been searching for the Huntington's disease gene, read reports by Francomano and others and noticed that the gene she suspected was responsible for achondroplasia had the same location as the one he'd zeroed in on for his study. Suddenly, the wheels started to turn.

Wasmuth quickly tested the gene in 16 achondroplastic dwarfs, and was astonished to find that 15 of them had an identical mutation on the far end of human chromosome four. His discovery signified one of the fastest jumps ever from locating a gene to pinpointing the exact explanation for a disease. "With Huntington's, it took 10 years, with achondroplasia it took 10 months," says Francomano.

Because the mutation is so consistent in those with the disorder, geneticists here have wasted no time in using a simple molecular technique to test for it. Last fall, Hopkins became the first medical center in the nation to offer in utero *testing for achondroplasia genes. Francomano developed the program, a combination of counseling, CVS (chorionic villus sampling, a technique for extracting fetal cells), and lab testing for the gene.*



DOUG MCDONOUGH

GARY PARKER

ABOVE: geneticist Clair Francomano, M.D. RIGHT: Joe and Ginny Foos, achondroplastic dwarfs, were expecting their first child. They had a 50 percent chance of having a healthy average-size baby, and a 25 percent chance of having a severely deformed baby that could not survive. Happily, Alexander Taylor Foos, a healthy achondroplastic dwarf, was born just weeks after this photo was snapped at the Little People of America Convention in Miami two years ago. Today, they also have an adopted dwarf daughter from Russia.

For couples like Beth and Kitt May the technology offers new possibilities. "Knowing that test is available makes a real difference in how we feel about everything," says Beth May, who's already talked with Francomano just, she says, "to find out what's going on."

The first person to have the test, Abby Tilkin, a Long Island clothing store manager, found what she and her husband hoped to hear—their baby is not double dominant. A boy, with the single gene complement for dwarfism, is due in late spring. "Relief is what I'm feeling," she says, "but even if the results would've been bad, I'd still have wanted to know."

Since genetic testing is fraught with ethical issues, Francomano says the team proceeds carefully in talks with parents. (Francomano teaches a class on genetic ethics each year at the noted Medical Genetics Short Course *in Bar Harbor, Maine) For couples like the Mays and Tilkins, where the double dominant is a possibility, choices are clear-cut. That will not necessarily always be the case.*

"So far, we've had no inquiries where only one parent is an achondroplastic dwarf and the couple wants to know if the baby's a child with dwarfism, but we could," Francomano says. "It's much too early in this game for us to have a rigid policy or practice; we're still exploring the ethical issues."

[1]*Not their real names*

Orest Hurko, who specializes in spinal dysplasias, was drawn to the field because, unlike most neurological disorders, those of little people are amenable to treatment.

Kevin also suffered recurrent ear infections that were relieved when tubes were placed in his ears. "In a number of the craniofacial dysplasias, the entire nose and throat is narrowed," explains Marsh. "Something about this skeletal arrangement ill-suits middle-ear ventilation, and ear infections are very common. So we know, with achondroplastic children to resort to inserting tubes for earaches much more quickly than we normally would."

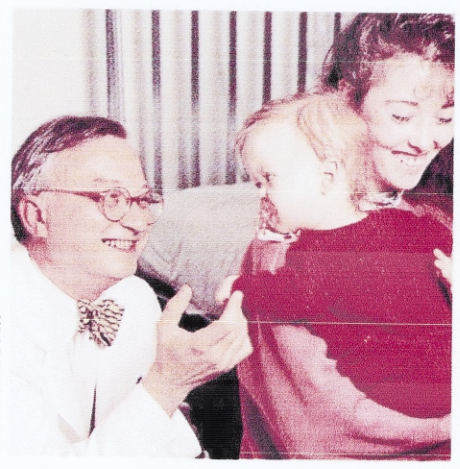
Medical procedures are part of the lives of most dwarfs, whether it be the relatively uncomplicated process of cleaning a trake, which the Leitzells learned to do routinely, or major surgery. Dee Miller, now 50, went most of her life without medical intervention, but four years ago she underwent a laminectomy, removal of a portion of the lamina of the vertebrae to relieve spinal compression. Before the surgery, Miller was experiencing progressive numbness in her legs and impaired walking. Now, she says, "I'm getting around just fine. It takes a lot to slow me down."

Amenable to Treatment

Such neurological procedures are frequently necessary for people with spinal dysplasias, because irregular skeletons constrict or slide against nerves. Sometimes it's only occasional, causing small discomfort; other times it's chronic and endangering. Neurologist Orest Hurko, M.D., who's made these cases a specialty and has a 400-patient base, was drawn to the field, he says, "because, unlike most other genetic neurological disorders I see, those of little people are amenable to treatment."

After several decades, Hurko knows the particular concerns of each disorder. With Morquio's syndrome, for example, patients

DOUG McDONOUGH



DOUG McDONOUGH

Orest Hurko (with Dee Miller at top) checking two of his patients. He cares for some 400 dwarfs.

may lack a vertebral structure in the neck that helps hold the skull on the spine. They face sudden death when the head, easily dislocated, pinches the spinal cord and brain stem; or they may face paralysis from a gradual whittling away of the spinal cord. Early treatment with braces or surgery to fuse the neck vertebrae or even the head to the neck can stave off life in a wheelchair.

With achondroplasia, the problem is too much nerve in too little space and subsequent compression. When the foramen magnum—the cranial opening for the spinal cord—is misshapen and too small, its bony surroundings dig into nerve tissue. In young children, where the problem is greatest, sudden infant death can be the unfortunate result. Removing bone to enlarge the foramen magnum is the obvious approach, but in the past the operation has had a fearsome mortality rate in children. "You're working in a very tight spot with extremely sensitive structures," explains Hurko.

Pediatric neurosurgeon Benjamin Carson, M.D., has devised a technique using high-speed drills to pare away bone at the back and sides of the foramen. He thins the bone down "to the thickness of a cornflake," then uses small curettes to peel off the remaining bone, bit by bit. Once the

Without treatment, many of these little people become wheelchair-bound.

sort of orthopedic treatment. Many achondroplasts, for example, have problems with kyphosis, in which the spine abnormally curves outward.

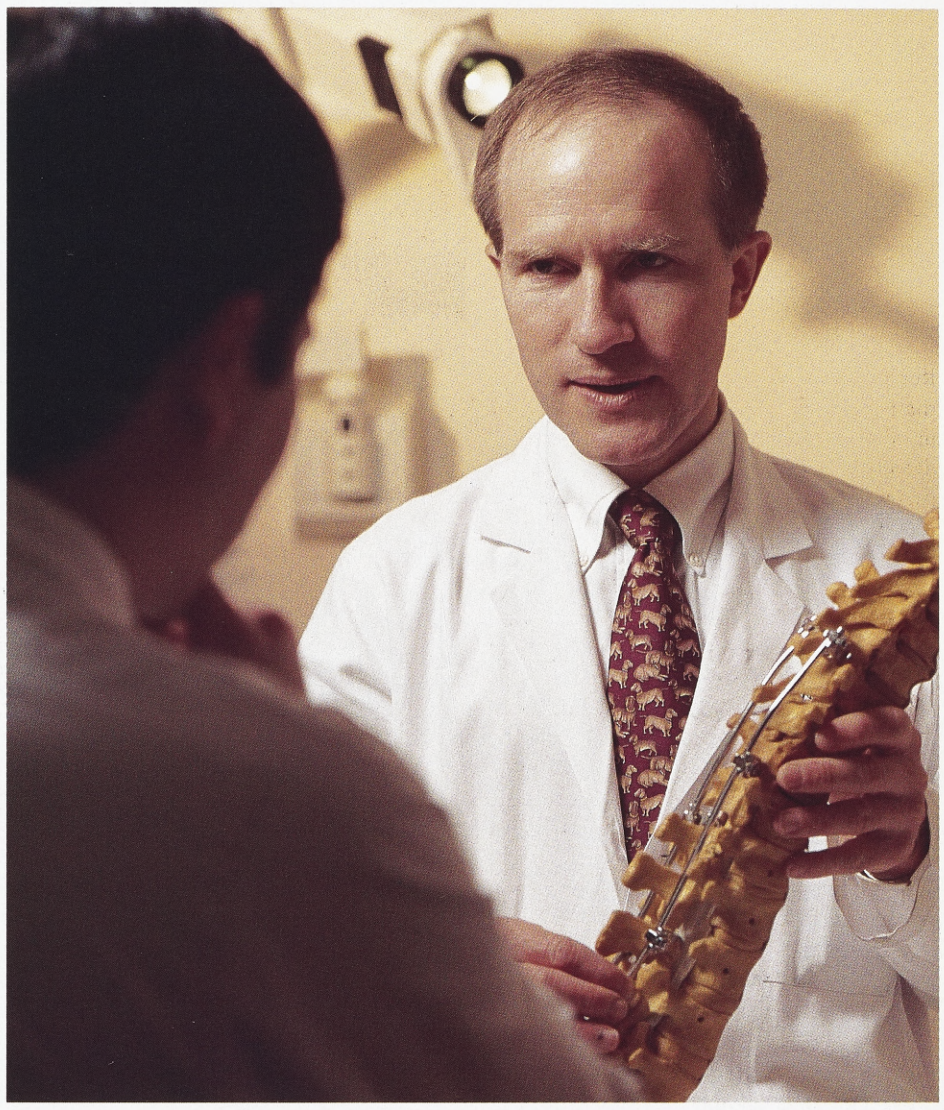
"Braces can be helpful," says pediatric orthopedic surgeon Paul Sponseller, M.D. "The problem comes in knowing when to brace. Many young children with this disorder have kyphosis early on but then outgrow it. Unnecessary braces can present problems of their own." Other spinal dysplasias, such as SED, may require complete joint replacement, which orthopedic specialists accomplish by using small tailor-made artificial versions of the joints.

And surgery often is the answer. Like the neurosurgery that is performed on dwarfs, orthopedic surgery for these patients is an evolving process, with new techniques being devised and procedures constantly being improved. Many little people, like 12-year-old Eboni White, are operated on as toddlers, for instance, to straighten the bowleggedness that is characteristic of certain forms of dwarfism.

A Generation of Progress

Eboni, an achondroplast, lives with her parents, Sue and Mack, White in a Maryland suburb near Washington, D.C. Sue White is also an achondroplast; her husband is of average stature. Mother and daughter were part of Francomano's study group to track down the gene for achondroplasia, and some of the differences in their orthopedic treatment highlight the progress that has occurred in a generation.

Eboni, who is now about 3′6″, will be taller than her 4-foot mother. "My legs are very bowed and I've never had them corrected," says Sue White, who is now 38 and grew up in D.C. "My mother was concerned, she always took me for annual checkups at Crippled Children's Hospital, and they considered surgery but they really didn't know how to do it. They talked about breaking my legs and resetting them, which we know today is the wrong thing to do. Even so, I was pretty active, I rode a bicycle, went roller-skating."



DOUG McDONOUGH

Paul Sponseller demonstrates how metal rods correct the spine, which may be curving outward in achondroplastics.

But Sue admits that she saw herself as somewhat restricted by her dwarfism, a quality she doesn't see in her daughter. "She's already shown me that she has far outpaced me when I was her age," she reflects. "She's so involved with school activities, she'll be the first to volunteer. When they have school dances, she'll just go. I would never have gone."

Young people like Eboni White and Kevin Leitzell personify a feeling of pride and self-worth common among today's generation of little people. They have had their way paved by increasing activism and antidiscrimination efforts by the Little People of America, by blunt-speaking role models like Dee Miller ("whatever you do," Miller says, sensing that a new acquaintance is not sure how to treat her, "don't pat me on the head") and, not least, by medical advances for which Johns Hopkins has been in the forefront. Step by step, those advances are allowing short-statured men and women to live longer, healthier, and more productive lives than ever before. ■

SHORTNESS NO OBSTACLE FOR PEDIATRIC SURGEON AIN

Michael Ain, M.D., doesn't deny that he has faced special challenges in his career—not because of things he couldn't do, but things people thought he couldn't do.

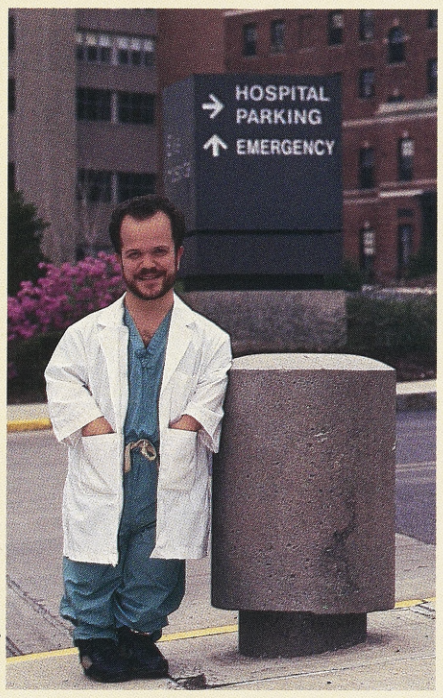
"I try not to think of anything as an obstacle," says Ain, who arrives at Hopkins this summer from Albany Medical Center to begin a fellowship in pediatric orthopedic surgery and who is an achondroplastic dwarf.

Born to average-sized parents on Long Island, Ain grew up with the attitude that "there was nothing that wasn't possible for me, even though it might be more difficult or take a little harder work than it did for someone else." At Brown University, he played second base for the college baseball team, describing himself as "quick in the field and a hacker at the plate."

A math major, he never felt that his 4'3" stature was an impediment to a medical career. He was drawn to medicine partly because of his own experience as a patient—as a boy he underwent surgery to implant ear tubes; when he was 19 he had high tibial osteotomies to correct the bowing of his legs-—but, more, he says "for all the corny reasons: I wanted to help people, I thought I could make a difference."

Ain doesn't hesitate when asked what the difficulties of medical school were for him. "Getting in," he says bluntly. "Many different medical schools told me I should not be a doctor because of my size."

The scrappy second baseman was hurt, angry and persistent. "I asked why and they couldn't give me a good reason," he says of his interactions with representatives from several different medical schools. "I said, 'Name one thing I can't do that someone else can,' and they couldn't. I was really scared that for the first time in my life someone was going to deny me what I wanted based on my height."



DAVID JENNINGS

But "I never doubted myself, I never thought they were right," Ain adds, and a year out of college, in his second round of applications, he was accepted at Albany Medical School. He had no problems in medical school because of his height, but faced similar apprehension when applying for a surgical residency.

Throughout the five years of his residency, which he also did at Albany, he has proved the doubters wrong with only minimum accommodations for his size. "It's no problem," he says. "Every hospital room has a footstool close by, beds come down low, there's stools all around in the OR. The sterile gowns are too long, but I just cut the bottoms off."

Michael Ain is one of only two physicians in the country who are dwarfs, according to a spokesman for the Little People of America. It's a distinction that Ain makes little of. "The way I hope people see me is—first impression: he's short. Then, within a couple of days, you forget I'm short and just see me for what I am and what I can do."

constricting bone is gone, he then expands the membranes that surround the spinal cord, which have been restricting it like a too-tight bandage. "Doing the operation this way," says Carson, "we find the complication rate is quite small."

In adults, as in the case of Dee Miller, problems settle on the opposite end, on the lower spinal cord. Low back pain is a traditional complaint of older people with dwarfism. Exercises or weight loss may give relief, but when too-small vertebrae constrict the spinal cord, patients may find themselves unable to walk. This symptom, called claudication, typically comes on after patients walk a few blocks. They may feel a tingling in the legs and then, if they continue walking, legs give way. Without treatment, many of these little people become wheelchair-bound.

The late Hopkins neurosurgeon Sumio Uematsu, M.D., modified a laminectomy procedure for these patients to open or remove part of the spinal canal surrounding the spinal cord, thus giving the cord more room. Since the conventional laminectomy opens only the one or two vertebrae that are pinching, patients may need repeat operations as other vertebrae become involved. Uematsu retooled the operation into an extended laminectomy, sometimes stretching, Hurko says, "from stem to stern," involving as many as 25 vertebrae.

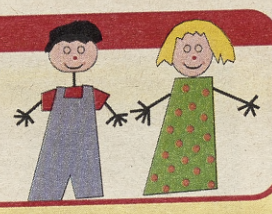
Since Uematsu's death last year, neurosurgeon Daniele Rigamonti, M.D., has added his own refinements to laminectomies. But it's not the skill of the surgery that's most difficult, he finds, but deciding who should get the operation. "It takes considerable experience to tell beforehand who would benefit," he says. Rigamonti and Hurko work together closely, combining their diagnostic and surgical experience to match patients with the appropriate procedure.

The Role of Orthopedics

Orthopedics is another specialty that often comes into play when treating little people. Since braces can help irregular skeletons assume more normal positions, most patients of short stature will have some

1997

CELEBRITY CLASSMATES



'MINI-ME' WAS A BIG MAN ON CAMPUS

HE'S ONLY 32 inches tall, but Verne Troyer was a big hit with his high school classmates.

TABITHA Verne's classmate

Verne, who soared to fame playing Mini-Me in "Austin Powers: The Spy Who Shagged Me," was so popular at Michigan's Centreville High School that he was elected homecoming king, recalls classmate Tabitha Shears Wolf.

"On graduation day Verne wore the smallest cap and gown I've ever seen," said Tabitha, who graduated with the diminutive star in 1987.

"Verne was very popular. He was outgoing and fun-loving. And he was the manager of the wrestling team. Everybody loved him and I don't remember anybody being cruel to him about his height. His friends would take turns lifting him up to the water fountain when he was thirsty.

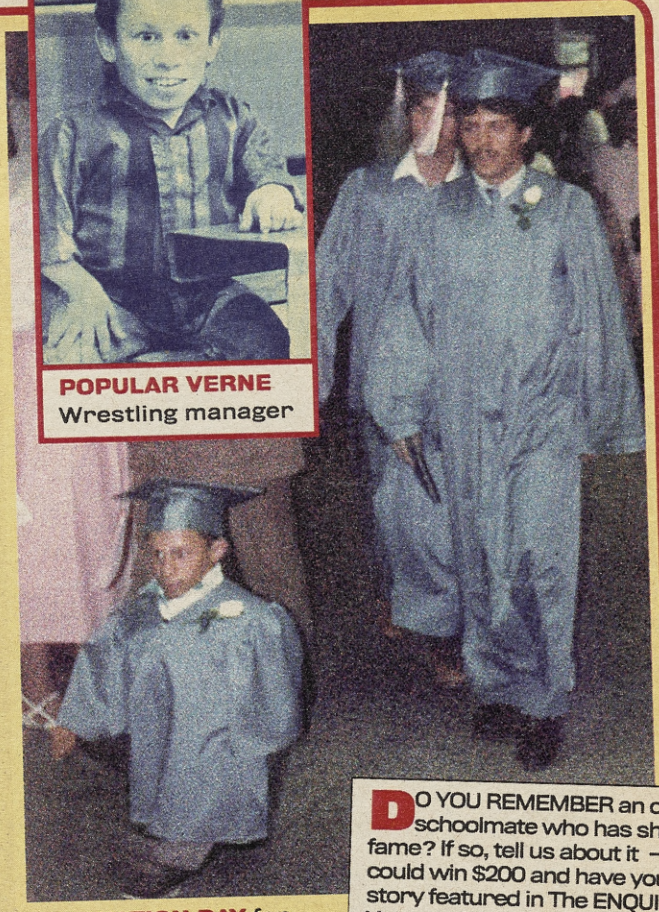
HOMECOMING KING Verne with his queen, Megan Olney.

"He even drove a car to school. It was specially rigged so that he could see and work the pedals."

After graduation, Verne, who at 2-foot-8 is one of the smallest men in the world, moved to Texas where he worked for a long-distance phone company. His Hollywood break came when he was cast as a stunt double for a 9-month-old in the 1994 movie "Baby's Day Out."

"I'm not surprised he made it big in show business," added Tabitha, now a court magistrate in Michigan. "We didn't vote him most likely to succeed, but I guess we should have!"

POPULAR VERNE Wrestling manager



GRADUATION DAY for Verne Troyer.

DO YOU REMEMBER an old schoolmate who has shot to fame? If so, tell us about it — you could win $200 and have your story featured in The ENQUIRER. Your story must be true and will be verified. Write a letter of 150 words or less and include your name, address and phone number. Send to: School Celebrity, c/o The National ENQUIRER, Lantana, Fla. 33464-0002. Or send e-mail to: letters@nationalenquirer.com

March 17, 1995

Pint-size movie veteran Billy Barty, 70, saved a lot of lengthy explanations by converting his walker into a question deflector before attending a Tinsel-Town bash. Billy's doing fine after his operation.

Online pick for most beautiful: Hank the dwarf

■ "People" magazine's Internet readers have flooded a poll with votes for Hank, the Angry Drunken Dwarf, a regular on the Howard Stern show.

The New York Times

Even to those with only the slightest grip on the pulse of popular culture, it will come as little surprise that "People" magazine has chosen the teen idol Leonardo DiCaprio to grace the cover of its annual "50 Most Beautiful People" issue, which hit newsstands this weekend.

Less immediately explicable is the ascendancy of Hank, the Angry Drunken Dwarf, in the magazine's online reader poll on the same subject, conducted via its World Wide Web site at www.pathfinder.com. By Sunday afternoon, Hank — a figure whose scabrous, unfailingly belligerent persona has made him a popular guest on Howard Stern's radio show — had garnered nearly 208,000 votes.

That was about 17 times those received by the second-place DiCaprio, star of the movie "Titanic." The contest runs through Thursday.

Some critics of the Hank write-in campaign dismissed it as a reflection of the cult following commanded by Stern, because it appears to have originated on an unofficial Howard Stern Web site before spreading across the Internet by e-mail. Others opined that the Net audience does not exactly represent the mainstream.

"Frankly, I think it's stupid," said Susan Toepfer, the executive editor of "People."

But many of the electronic campaigners themselves insist their message is more sophisticated — an attempt to use the new media to challenge the cultural hegemony of the old media..

"The 'media' tells us what food to eat, what movies to see, what music to listen to, who to vote for politically and what kind of people are attractive enough to have relationships with!" one Internet iconoclast wrote. "Voting for 'Hank the Dwarf' is a reflection of how the people really feel about media!"

Hank voters say they are trying to make a symbolic point by touting a candidate who has become the antithesis of celebrity culture appearing on Stern's show in a drunken stupor, vomiting on himself and falling down stairs.

Representatives from "People" said last week that Hank will never appear on the cover of the magazine. But Dan Okrent, editor of new media for Time Inc., said the Web site will honor its promise to give the winner a home page.

"Somebody asked me, 'What are we going to do about this?'" Okrent said. "And I said, 'We are going to stand here and be bemused.' This is a big open forum. It's not intermediated by those of us who 'control the media.'"

May 1998

Former munchkin on brick road again

Margaret Pelligrini, one of the original munchkins in "The Wizard of Oz," is on the yellow brick road again.

She's recreating her role for a stage production of the classic film. "I'm going back to Munchkinland. That's going to be real exciting to play the part I played 60 years ago," Pelligrini, 75, said recently before a rehearsal at the Lancaster Opera House in Lancaster, N.Y.

Though she has revived the role countless times, the energetic actress took nothing for granted for this production. She double checked her cues with director **Thomas Kazmierczak** and admitting to a few jitters.

"I don't want to mess up all his work," she said.

Pelligrini is being joined by two of her movie co-stars, **Jerry Maren**, a Lollipop Kid, and **Karl Slover**, a munchkin trumpeter.

12-13-98

THE LONG AND THE SHORT OF IT: "Austin Powers: The Spy Who Shagged Me" star Verne "Mini-Me" Troyer, who's 2-foot-8, really looks up to 6-foot-6 basketball great Charles Barkley. The two ran into each other at the ESPY sports awards in Ve

GRUNT WORK: Redding powerlifter Doby Jennison strains to press 275 pounds during a workout at the YMCA last week. With a lifetime-best bench press of 301 pounds, Jennison holds the distinction of having lifted three times his own body weight.

John Stubler / *Record Searchlight*

Little Big Man

Pound for pound, he may be state's best

By Rob Shore
Record Searchlight

Quick, think of the sport of powerlifting. What type of athletes did you imagine?

Maybe you flashed back to the Atlanta Olympics. Who did you see on the medal stand for the clean-and-jerk? Most likely, some 6-foot-several behemoth with a neck as big as your torso.

In that case, you didn't think of Doby Jennison. Jennison, a 34-year-old Redding resident, is pound-for-pound, perhaps the top powerlifter in California, but you'd never mistake him as such.

He's 4-foot-2, and when he's in competition shape, his weight hovers around 100 pounds. Actually, as he prepares to undergo back surgery to repair a condition related to his dwarfism, he's ballooned somewhat — maybe to 106 or 108.

"A little bit," he said. "I should just gain weight and lift at 114. But then I wouldn't win the pound-for-pound."

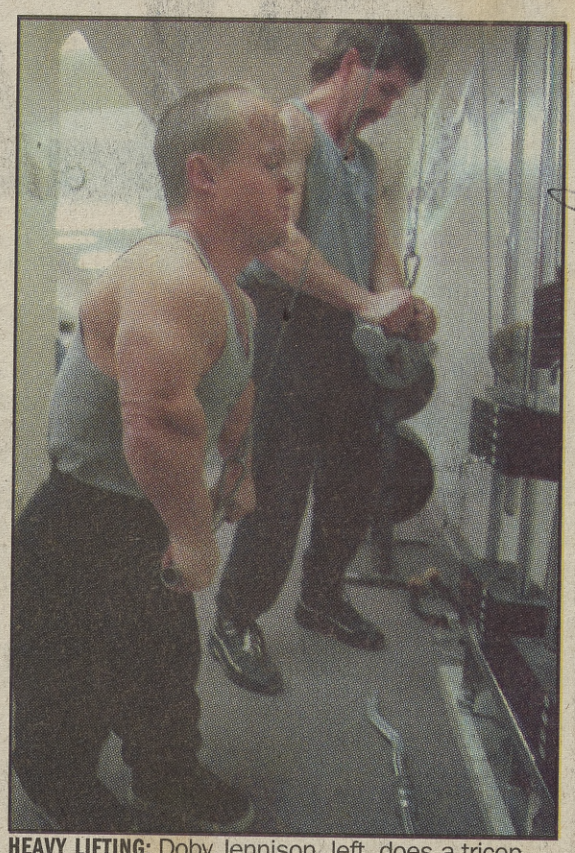
Jennison did capture the pound-for-pound title at his last competition in November, the American Powerlifting Federation state championships. To do that, he benched 297 pounds — nearly three times his body weight.

Not bad for someone who admittedly has only been working out "seriously" for two years.

Jennison's training regimen, which he follows in daily workouts at the Redding YMCA, is far from scientific. He works out six days a week (the YMCA is closed Sunday), but doesn't have a set routine.

Mainly, he just works on the upper body — biceps, triceps and chest — until he gets tired.

See *Lifter* C-4



HEAVY LIFTING: Doby Jennison, left, does a tricep pulldown next to Scott Dorman of Anderson. Since starting to work out seriously two years ago, Jennison has become one of the top pound-for-pound powerlifters in the state.

Jan. 1999

Continued from C-1

Then he moves on to another station.

"I just play it by ear," he says. "I guess I need to get more scientific."

The key part of any Doby Jennison workout, though, is the bench press. After waiting patiently for the station to open up, Jennison goes straight for the 45-pound plates to load onto the bar — plates that are not much smaller than he.

"This is the hard part of working out," he says with a grin. "Getting the weights over to the bar."

Jennison warms up with a few reps at 135. Then, he slowly builds up to 235, where it becomes apparent that he's starting to feel the weight. With each successive lift, his face scrunches up like a closed fist and turns beet red.

"This is where it gets hard," he said with a last gasp.

Finally, he manages one rep at 275 pounds. Jennison is a bit disappointed, especially after hoisting 297 (his all-time high is 301) just three months ago.

When Jennison undergoes back surgery, he'll be laid up for three to four months. Then, he'll come back slowly, doing some easy lifting, some easy bench work and even a little work on leg strength, an area he hasn't pursued much.

But ideally, he'd like to take at least one more shot in a major competition.

"One of the federation's record is 313, and I think I can get that," he says.

He'd also hopes to someday lift 3½ times his body weight — something he thinks might be a world record.

Whatever happens, you won't hear Jennison complain about the cards that have been dealt to him in life — though it would probably be easy to do so. He's adapted well to his dwarfism; he doesn't even think about it much.

In some ways, he's been very lucky, even with his current back problems.

"I've been told I'm lucky," he said. "A lot of dwarves are not walking when they're 30 or 40. A lot are in wheelchairs from childhood."

Advocacy group draws hundreds to regional conference in San Jose

PENNY DE LOS SANTOS — MERCURY NEWS

Connie Eisenbraun, 35, of Riverside and Steven Wilde, 17, of Houston greet each other with an embrace at the Little People of America conference in San Jose.

Little people overcome world's big challenges

BY JOHN WOOLFOLK
Mercury News Staff Writer

The little things are often the biggest pain for little people.

"It definitely brings on a constant frustration, not being able to reach things or fit comfortably into furniture," said Peggy O'Neill-Laise, who is 3 feet 8. "How can I reach the sink? How can I reach the person behind the counter to pay my bill?"

O'Neill-Laise was among 200 people who gathered in San Jose this weekend for a regional conference of the Little People of America, the advocacy group established by diminutive actor Billy Barty in 1957 for people under 4 feet 10.

For little people — the term they prefer to "dwarf" or "midget" — such gatherings are a chance to meet others like them and share strategies for dealing with a world that literally looks down on them.

"Little people are stigmatized," said O'Neill-Laise, a therapist and motivational speaker from Ojai. "We're stared at, laughed at and pointed at. People think our height has something to do with our intelligence or capabilities."

Documentary filmmaker Dan McKinney, 27, blames Hollywood for making comic figures of little people in everything from the Munchkins in "The Wizard of Oz" to Mini-me in the "Austin Powers" sequel.

"They're not portrayed as real people with children and jobs," said Mc-

See ***LITTLE PEOPLE****, Page 2B*

Amy and Matt kick up the dust with their children, *left to right*, Molly, five, Jeremy, nine, Jacob, two, and Zach, nine.

a little bit different

She's 4 feet 2, but Amy Roloff has never let her size stop her from getting a lot out of life. Here, she shares her unique perspective and what she's teaching her kids about faith and acceptance.

BY AMY ROLOFF, AS TOLD TO MICHELLE MANDEL PHOTOGRAPHED BY DALE BERMAN

My first day of kindergarten was the day I realized I was a dwarf. Everyone stared at me when I walked into the classroom. I wasn't much shorter than the other kids, but my big head, short limbs and bowed legs—characteristics of achondroplasia, my type of dwarfism—marked me as different. Nobody teased me or called me names, yet I felt like an outcast because I didn't look the way they did.

From that day on, I was convinced that people disliked me because of my size. I avoided social situations and didn't make many friends. When I got older, I rarely dated, and I wondered if any man would ever love me. I couldn't imagine that I'd become a mother, and I wanted kids more than anything. I often prayed, asking God why I couldn't be taller like everyone else. I wouldn't really understand his answer for years to come.

A lifetime of never really fitting in

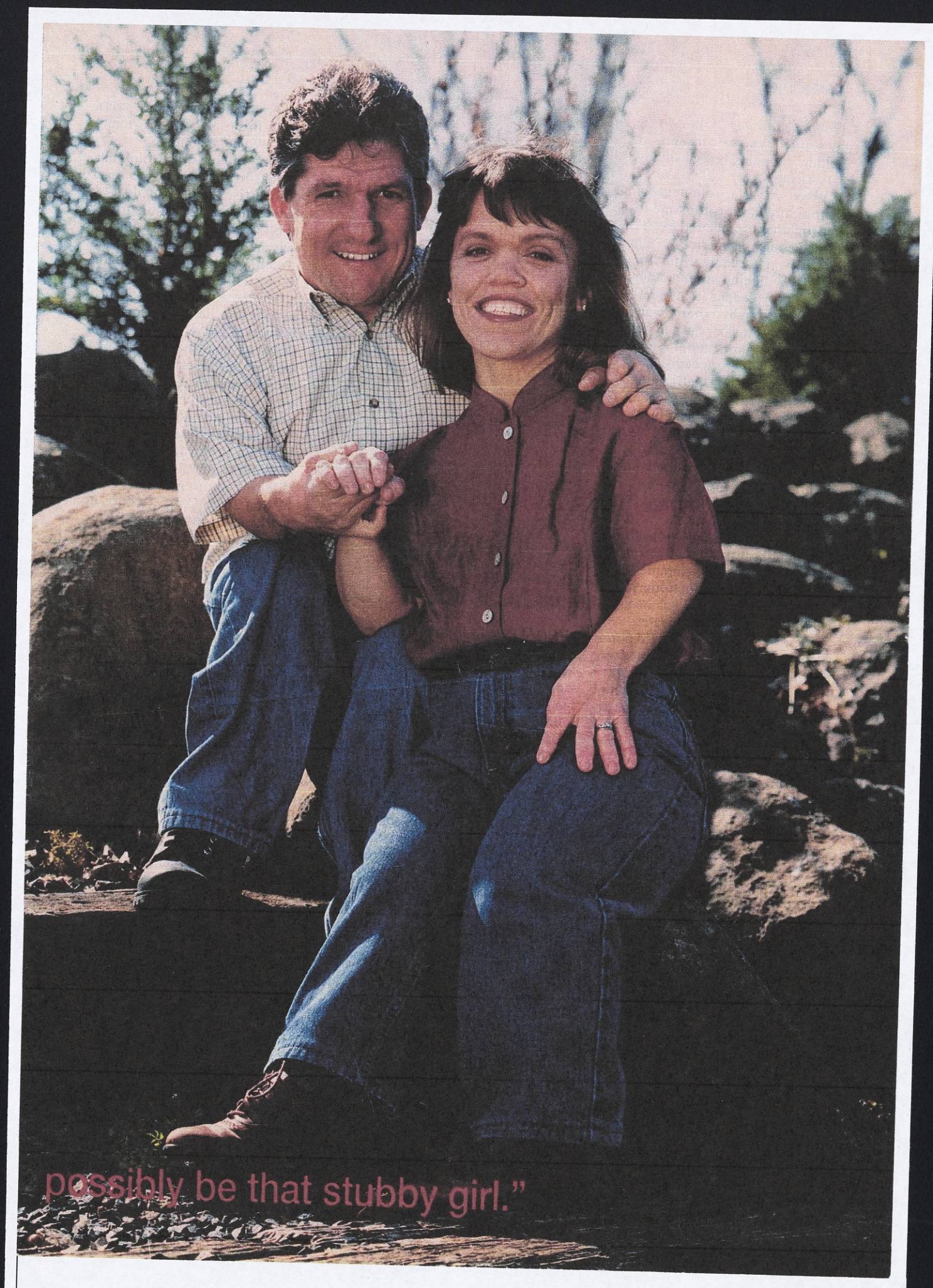
My parents got a shock when I was born on September 17, 1962. My two older sisters (and my younger brother) are average size, and no one on either side of the family is a dwarf. My folks would soon learn that anyone can have a dwarf child.

I'm sure my condition must have bothered my mom and dad, but they never said a negative word about it. They were determined to raise me just like any other kid. We lived in a suburb of Detroit (my parents are now both retired—my dad was an architect, and my mom was a secretary), and nothing in our house was altered for my height. Knowing that I'd constantly face obstacles in the tall world, my parents wanted me to learn to adapt and to be a problem solver. The phone was up high, and so was my closet clothes bar. I had to stand on a stool to reach everything.

As a result, I've always been fiercely self-sufficient. I've never wanted my shortness to be an excuse or a way out of a difficult task. These days, for instance, I desperately need a housekeeper. Still, I won't hire one because I think I should be able to handle the cleaning myself.

Learning how to reach a light switch, though, was a lot easier than dealing with the emotional aspects of my condition. It sounds weird, but I didn't think of myself as short. In my mind, I pictured myself as bigger—just different from everyone else. It always surprised me when I walked ▶

"When I walked by a mirror, I'd think I could not



possibly be that stubby girl."

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by a mirror and saw myself—I couldn't possibly be that stubby girl staring back.

When I was in elementary school, my parents took me to get-togethers sponsored by the Little People of America (LPA), a national organization for dwarfs. But being around other dwarfs only deepened my feelings of self-doubt. I didn't want to believe I could be one of *them*!

Yet at the same time, I never really fit in with my peers. I was the only dwarf at my high school, and while I had a few girlfriends, I didn't feel comfortable at school games and parties. I've always found it hard to talk to people way up there when I'm way down here. And I couldn't dress like the other girls. I shopped at the stores they did and had the clothes tailored to fit me, but the effect was never quite the same. For example, I bought a pair of bell-bottoms in junior high, and when I got them shortened, the bell disappeared.

Standing tall: Amy takes pride in the life she's built.

Every so often, though, I'd corral my insecurities and do something daring. One year in high school, I tried out for the pom-pom squad. I figured I could be the small girl on top of the pyramid. But I didn't make it. I did get into the marching band and played the clarinet. In spite of my short legs, which made it hard to keep up with the group, I managed.

I had crushes on average-size boys, but I convinced myself that they wouldn't like me. On prom nights, I sat home feeling sorry for myself and envying the girls who had dates.

When I was 17, I went out with a little person I met through LPA. It was a disaster. We were both so shy we barely spoke to one another.

In college, at Central Michigan University, my social life didn't improve at all. When my roommates talked about their sex lives, I just sat there stone-faced. I couldn't participate in the "you like him, he likes you" sort of thing because it had never happened to me.

I later learned that my roommates thought I was a snob because I didn't join in their conversations. One day they told me to lighten up and start living life, and their words shocked and exhilarated me. All along I had convinced myself that my size repelled people, when in fact I was the one pushing people away. Once I started opening myself up to others, my life slowly began to change.

The courage to find romance

After I graduated from college in 1985 with a degree in personnel and hotel/restaurant management, I got a job as a secretary at a window-washing company. While I enjoyed work, the rest of my life was boring. I was 23 and back living at home. I wasn't dating, and I hung out with my friends from high school. I prayed for a husband and children, but, given my poor track record with men, I never thought I'd get them.

I finally decided that if I wanted a family, I'd have to make an effort. I was shy around most tall men, and they didn't approach me, so I decided to try to meet dwarf men. In the summer of 1986, I went to an LPA conference in Dearborn, Mich. Instead of cringing every time I saw a little person, as I had done when I was a child, this time I felt drawn into their world. I belonged.

I first spotted Matt Roloff at a weight-lifting event. (His form of dwarfism is diastrophic dysplasia, meaning that his joints don't connect properly and his legs are crooked. He has to use crutches to get around.) I could tell by his outgoing personality and by the way people responded to him that he was someone I wanted to know. Friends introduced us, and when he told me I was the best-looking woman at the convention, I couldn't believe it. I'd always thought I was pretty, but no one else had ever told me that before.

When I returned home from the conference, I couldn't stop thinking about Matt. He lived in San Jose, Calif., where he worked as a computer-software programmer, and I tossed caution to the wind and sent him a letter. It was just a "hi, how are you?" kind of note, but as I wrote, I remembered his warm brown eyes.

Matt wrote back, and that fall, we exchanged letters and talked on the phone often. I learned that Matt had spent a total of about three years of his childhood in hospitals for surgeries to correct his club feet, which were caused by his dwarfism. Doctors had also tried to straighten his twisted legs by cutting away the bone, with little success. He'd lain in head-to-toe body casts for months on end.

But Matt never felt sorry for himself. Instead of thinking no one liked him, as I had, he became the neighborhood magnet, drawing hordes of average-size kids to his house to build go-carts and car engines. The bigger the obstacle, the more determined Matt was to mow it down.

Six months after we met, Matt invited me to visit him in San Jose, and I went. I was scared—I'd been on maybe half a dozen dates before and barely even kissed a man—but my heart told me Matt was special.

It was the best week I'd ever had. Matt showed me around San Francisco, and we toured the wine country just north of the city (Matt and I can both drive; we use pedal exten- ▶

"My college roommates thought I was a snob."

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sions). We ate big steak dinners at fancy restaurants. I knew I had finally found the man of my dreams.

How her prayers were answered

I visited Matt again in May of 1987. During that trip he took me to Yosemite National Park, and we sat on a rock ledge overlooking a beautiful valley. He put his arm around me and kissed me, and then he pulled out a diamond ring and asked if I would be his wife. I was so incredibly happy, I started crying. I said yes, of course.

Four months later we married, and I moved to San Jose. I got a job as a secretary at a computer company. A year later, Matt and I decided to start a family. Though most dwarf women have normal reproductive systems, for some reason, I couldn't get pregnant without fertility drugs. When my doctor told me I was expecting twins, I was shocked. I wondered if my little body could handle carrying two babies at once. But my obstetrician saw no reason to be concerned.

There was a good chance one or both of our babies could be dwarfs, but Matt and I decided that didn't matter. We believed our own experiences would give us invaluable insight into raising a dwarf child.

When I was six months pregnant, an ultrasound revealed we'd have one dwarf and one average-size baby. The twins were born in May 1990. Like all dwarf women, I had a C-section because my pelvis was too small for me to deliver vaginally. Zachary is an achondroplastic dwarf like me, and Jeremy is average height. At nine, Jeremy's already taller than his parents!

Just before the boys' birth, we had moved to a 34-acre farm in northwestern Oregon, where we live today. Matt had a new software development job, and I stayed at home.

But when the twins were 16 months old, we had a scare. Zach was diagnosed with hydrocephalus, or water on the brain, a condition that many dwarfs develop. I flew with him to Johns Hopkins Children's Center in Baltimore, where doctors drained the fluid from his brain. He's fine now.

I've since had two more children—Molly, five, and Jacob, two—who are both average size. I spend all my time taking care of my family and our home. In his free time, Matt has turned our farm into a fairy-tale land for our kids. He's built a full-size pirate ship and a three-story tree house, and he's almost finished a western town, complete with a sheriff's office, saloon and jail. He's also constructing something called a Tower of Terror, but I don't want to know what that is.

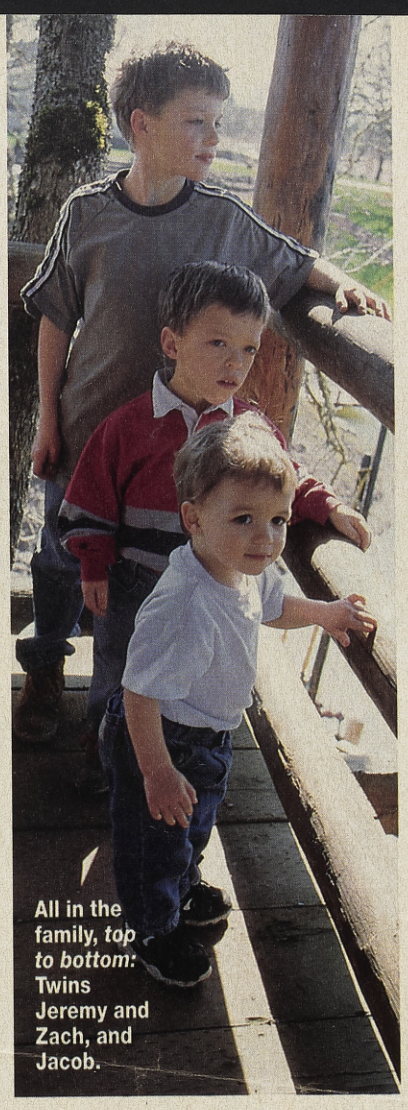
We get stared at a lot. I probably look funny when I go to the supermarket—a dwarf mom whose head barely reaches the top of the shopping basket, heaving a full-size toddler into the seat and being trailed by three children, one of whom is a dwarf. It really surprises me sometimes when people ask how many of the children are mine. I usually reply with a smile, "All of them," and always receive a look of complete amazement.

I am trying to teach my children how to handle strangers' curiosity about dwarfs and to not be embarrassed when people ask them questions about us. I think I've been successful. Once a girl asked Molly why her mother was so small, and Molly answered deftly, "She's a little mom, can't you see that?"

It's difficult for Zach sometimes. He can't keep up with Jeremy and their average-size friends on the soccer field, and he gets stared at sometimes by other kids. When that happens, I encourage him to go up and introduce himself, because they probably won't approach him first. I tell him—and our other children too—that God doesn't make mistakes.

I used to believe that I was destined for an unfulfilled life. But now I know that was never God's plan. I just had to learn to love myself before I could make my dreams come true.

I'm so lucky to have found Matt. Nobody else could have taken me on such an adventure. That's how I see our life: one giant adventure. ■



All in the family, *top to bottom:* Twins Jeremy and Zach, and Jacob.

What is a dwarf exactly?

Little People of America defines dwarfism as an adult height of 4 feet 10 or less caused by a genetic condition. A dwarf child may be born because one or both parents carry a "dwarf gene" or as a result of a random genetic mutation. There are about 100 variations of dwarfism. Achondroplasia, Amy's type, and diastrophic dysplasia, Matt's type, are two of the most common kinds.

Q. Is there any way to find out if you have the dwarf gene?

A. No. But through amniocentesis or ultrasound a pregnant woman can find out if she's carrying a dwarf child.

Q. What are the odds of giving birth to a dwarf baby?

A. The chances depend on the type of dwarf. Achondroplasia occurs in one of every 14,000 births; diastrophic dysplasia, once in 110,000.

Q. What is a midget?

A. This term is often used to describe dwarfs who have the same proportions as average-size people. But the word is considered offensive. *Little person, person of short stature* and *dwarf* are all acceptable terms.

To learn more, contact the LPA national headquarters at Box 745, Lubbock, TX 79408, or call 888-LPA-2001. You can also visit its Web site at www.lpaonline.org.

"I tell my children God doesn't make mistakes."

Buford's little big man

T. LEVETTE BAGWELL / Staff

Josh Phillips (left), 16, works with his engineering teacher, **Phil Ducote,** (in glasses) and fellow student **Amanda Mireles** at Buford High School as they look over some sample plans. Josh wants to become an engineer.

Teenager occupies giant place in hearts of students, teachers

BY BILL SANDERS
bsanders@ajc.com

Josh Phillips roams the halls of Buford High School like he owns the place.

Classmates high-five him. Some yell his name from the other side of the lockers.

Spanish teacher Vallorie Coley sees Josh turn the corner after school, and a smile takes over her face.

"I just adore that guy," she says later.

Josh Phillips, 16, is easy to pick out. He's the 3-foot, 2-inch giant on campus who has endured 27 operations in his short life — and he's not done.

He's also not complaining.

His teachers love him. And his football teammates — he's a team manager, but he's still a teammate — respect him and look out for him.

This afternoon, he'll be on the sidelines at the Georgia Dome as Buford faces Decatur, with the winner advancing to next week's Class AA state championship game.

"Josh, he's all right" said Darius Walker, Buford's all-state running back. "He's cool."

Despite his physical limitations, Josh — a dystrophic dwarf — doesn't require many special accommodations at school. He does have a locker by each of his classes — toting books all around school would be a heavy burden. And he gets to stretch his legs in class pretty much whenever needed.

And then, there's the special bathroom perk he enjoys at Buford. That's a big one.

It's true that Josh's dwarfism makes him a bit of an inadvertent celebrity on campus. But that wears off. What doesn't is the contagious spirit he displays.

"This is who I am," Josh said. "And I'm having fun.

➤ Please see **JOSH, A11**

Josh: Student is giant in others' eyes

➤ Continued from A1

"Special needs kids are often born to special parents, who have special spots in their hearts."

Determined parents

Renee Phillips has heard that 100 times, and laughs every time.

"I say I got Josh because I'm hard-hearted, logical and determined," she said. "Not hard-hearted in the sense that I don't feel for him and love him, but we're just very determined that he lives an independent life and is treated like other kids."

Going back 16 years to when Reneé and Joe Phillips first learned that Josh would be a dwarf, the only thing Reneé was worried about was: medically, would he be OK?

"I went to school for 12 years with a dwarf, so I didn't immediately think, 'Oh no, what a horrible life.' Everyone in our family has short legs anyway," she said.

The first conversation she remembers with doctors at Scottish Rite was them telling her their lives would be surgery, surgery, surgery.

"A parent there with a dystrophic dwarf like Josh told us it would become like taking your car in for maintenance," she said. "I thought, 'Never, never, never.' Now, 16 years and all those surgeries later, it is like the next repair. It becomes second nature."

Such matter-of-factness is tempered with a mother's love for her son.

"It was really devastating when growth spurts hit his peers," she said. "That first happened when he was 4, in kindergarten. He'd pretend to be sick at school so he didn't have to go outside to the playground because he kept getting knocked off equipment or pushed down when he was in front of the line.

"That was heartbreaking — a 4-year-old kid not wanting to go to the playground."

Josh shrugs off most of his early school woes.

"Everyone was my height when I started school, so no problem there," he said. "In middle school, with hormone changes, there was a little of the 'let's pick on the little kid.' They'd walk by me and push me down. But I grow stronger from misery. I knew, even then, if they did it once, they'd do it again. So I started working on a sense of balance, and I gained a stronger one from that."

Several years ago, Reneé Phillips typed up a letter that she sends to all of Josh's new teachers, coaches or scout leaders. It's an introduction to Josh. It's also a plea.

"Dwarfs are not mentally handicapped in any way," her letter states. "Although difficult to use, the word dwarf is a perfectly acceptable one. Dwarfs use it themselves and we have found it to be the most clear and descriptive term . . .

"Please let Joshua do as many things for himself as he can . . . He is very knowledgeable about his conditions and limitations. He however gets very tired of being different and will sometimes be angry at his predicament. This is no excuse for failing to do his work or for a disruptive attitude."

Photos by T. LEVETTE BAGWELL / Staff

Josh Phillips (right) and **Landon Saunders,** equipment managers for the Buford High School football team, unload laundry.

Nowhere in the four-page letter is there a hint of emotion — just the facts.

No one pushes Josh down anymore. No one would dare. He has about 70 bodyguards from Buford's 13-0 football team.

School, indeed, has become pretty good.

One consideration

But if Josh is mostly treated like every other Buford High student, there is a time when he enjoys special consideration.

When need be, Josh gets to use the administrators' bathroom, in the front offices. A specially made stick with a couple of hooks attached waits in the corner of the bathroom. The device helps him undo his pants, then pull them back up. It allows him to reach the light switch. A foot stool helps him reach the sink to wash his hands.

"I do have some bathroom needs, and things like that make me really glad I'm at Buford. If I was at a bigger school system, getting all of these things might take an act of Congress or lots of paperwork. Here, I pretty much get what I need."

He's gone to school with many of the students all of his school years. The only ones who are uncomfortable around him now are freshmen, and that only lasts a few days.

"They'll pretty much walk around in circles to avoid me at first," Josh said. "And then when little kids see me in the mall or something, they are afraid of me at first.

"I actually love it when little kids come up to me in public and ask questions. Their parents are always acting like they are going to punish the child for asking me what they think are embarrassing questions, but I tell them, 'I like it, don't make them stop.' "

There are some questions he can't answer. Like how he was born with a type of dwarfism that is strictly hereditary yet no one can trace a dwarf on either side of his family.

If there's one area where Josh gets squeamish, it's talking about girls. Of course, many 16-year-old boys can get that way.

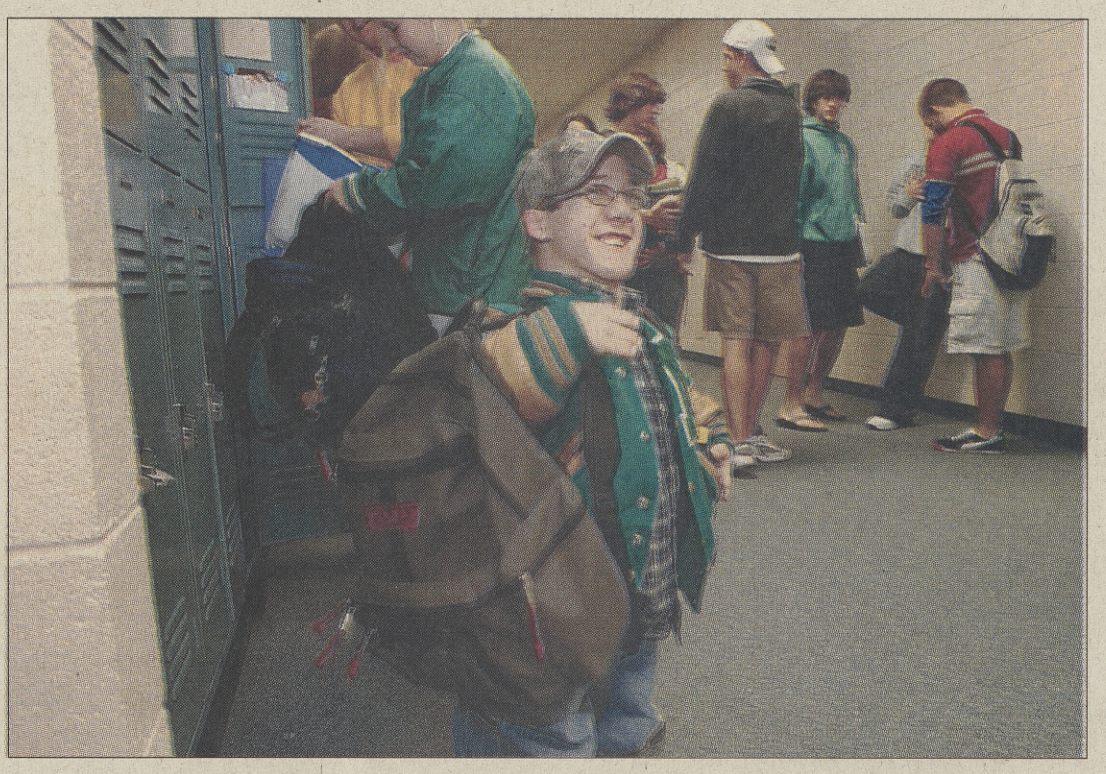
"I don't really have time and don't want to spend the money," Josh says of dating.

His mom knew there would be emotional challenges.

"One of the tough steps was when he was starting high school," she said. "High school meant girls and dances and cars. That was tough. He decided he simply wasn't going to go to high school. We said, 'Yeah, you really are going to go.'

"Once he got there, basketball kicked in and he was with his friends, and he saw everything was going to be OK again."

Over the last couple of years, he has started attending LPA — Little People of America — meetings with his parents. His folks have gone most of Josh's life, finding the meetings educational and sometimes inspirational.



Josh Phillips straps on his backpack and prepares to go to his next class at Buford High. His mother has told his teacher that his condition "is no excuse for failing to do his work."

Others have problems

No one in Josh's family ever asks: Why us? At least not for long.

Here's Josh's answer:

"When I start leaning that way, I'll see something that shows me why it's this way," he said. "This summer, I was at a Boy Scout outing and there was a kid there who had severe allergies to nuts and milk and was slightly mentally challenged.

"After camp, his mother wrote me a letter and said how much of an inspiration I was to her son. She said before that camp, her son was crying himself to sleep every night and now he wasn't. That he saw I could do things like that, so maybe he could, too.

"That's why I'm like I am, and I had to say 'Thanks, God, for reminding me.' "